2005

Determining the level of consumer involvement in healthcare

Karen Patterson

University of Wollongong

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DETERMING THE LEVEL OF CONSUMER INVOLVEMENT IN HEALTHCARE

By

Karen Patterson

A thesis submitted in partial fulfilment of the requirements for the degree of

Master of Midwifery (Research)

University of Wollongong

Faculty of Health & Behavioural Sciences

Department of Nursing

2005
I, Karen Patterson, declare that this thesis, submitted in partial fulfilment of the requirements for the award of the degree Masters of Midwifery (Research), in the Department of Nursing, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Karen Patterson
August 2005
ACKNOWLEDGMENTS

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Professor Patrick Crookes – UoW Academic Supervisor

Dr Allison Shorten – UoW Academic Supervisor

Dr William Millward – Critical Friend and Editorial Guidance

And most importantly my husband Brett and children Katie-Louise, Vaughan and Lochlan for their unconditional love and support
Health and consumerism is a partnership featured in many Western developed countries.

Nearly a decade ago, the National Quality Taskforce and Advisory Council recommended the adoption of a consumer oriented approach as being fundamental to providing safer services, minimising preventable adverse health outcomes, whilst also improving healthcare quality. In accordance with this recommendation, it is now commonplace for healthcare organisations to incorporate the consumer oriented philosophy into their mission statements. In addition, healthcare recipients tend to be referred to as consumers in preference to the traditional term patient. Despite organisational commitment for change and reports of consumer satisfaction with acute care services in Australia (AIHW 2000), the findings from the Bristol Inquiry (2001) and the King Edward Memorial Hospital Inquiry (2001) suggests that there is an absence of consensus as to the impact of these initiatives on the delivery or quality of frontline healthcare.

This study aims to determine indicators of consumer participation in the planning and delivery of healthcare in an Australian context. The practice of consumer participation at the individual level of frontline healthcare is examined specifically for indicators of active participation in both decision making and information sharing. This study is complimentary to Phase Two of a Commonwealth funded project designed to explore clinical teams and the organisation of care related to the clinical condition, elective caesarean
section. The study’s participants have been determined by the Commonwealth project, with the study’s samples being drawn from the recipients and providers of elective caesarean section healthcare, in three Queensland public hospitals over a three month time frame.

A multi-method approach is utilised to navigate the complex social and professional constructs that impact on the organisation and recording of elective caesarean section healthcare. Triangulation of the environmental, clinician, consumer and medical record data from the three study sites allows for a greater understanding of the relationships between and within the data sets.

The medical record audits tendency to lack evidence of consumers actively participating in information sharing and decision making is shown to be a reliable representation of the environments inability to support participation, and the clinician and consumer samples passive view of participation at the frontline of healthcare. The triangulated data also clearly demonstrates the diversity of views and behaviours that clinicians hold in relation to the involvement of consumers in healthcare and that in the main consumer involvement is not valued. In relation to the quality and safety of healthcare, aside from the clinician’s views on consumer participation, the absence of accountability to utilise standardised forms, function collaboratively or communicate clinical care effectively suggests that the study sites have numerous professional and governance issues that have yet to be effectively addressed.

In focusing on the individual aspects of the healthcare experience this study demonstrates that collection and aggregation of consumer satisfaction data to be an unreliable indictor of healthcare quality. This study demonstrates a potential relationship between expectations of healthcare and satisfaction with healthcare. Women who felt fully involved in decision making often claim to be dissatisfied with that level of involvement and women who felt uninvolved are often satisfied with not being involved. In order to satisfy consumers and secure a positive health outcome measure, the study findings suggest matching
expectations with experience, and this would involve an active level of participation. However, meeting the consumer’s expectations and generating satisfaction should not be interpreted as representative of meeting the technical quality or service delivery standards.

This study contributes to the limited body of research relating to consumer participation at the individual level of healthcare. The study demonstrates that overall the level of consumer involvement in healthcare is marginal. Inconsistency in beliefs and behaviours and an ad hoc approach to organising and communicating clinical care ensures the passivity of the healthcare recipients and brings into question the true quality and safety of Australian healthcare.
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<tbody>
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<td>New South Wales</td>
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<tr>
<td>PNC2</td>
<td>Prenatal Card Version 2</td>
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<td>TURP</td>
<td>Transurethral Prostatectomy</td>
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<td>ECS</td>
<td>Elective Caesarean Section</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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<td>CHF</td>
<td>Consumers' Health Forum</td>
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<td>AHMAC</td>
<td>Australian Health Ministers' Advisory Council</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>Australian Council for Safety and Quality in Health Care</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>ACHS</td>
<td>Australian Council on Healthcare Standards</td>
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<td>SCRCSSP</td>
<td>Steering Committee for the Review of Commonwealth / State Service Provision</td>
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<td>CFC</td>
<td>Consumer Focus Collaboration</td>
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<td>EPOC</td>
<td>Effective Practice and Organisation of Care Group</td>
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<td>VBAC</td>
<td>Vaginal Birth after Caesarean Section</td>
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<td>ICD</td>
<td>International Coding Dataset</td>
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<td>CRM</td>
<td>Cardiovascular Risk Management</td>
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<td>APO</td>
<td>Active Patient Orientation</td>
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<td>GP</td>
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<td>RMO</td>
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<td>VMO</td>
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<td>NRCCPH</td>
<td>National Resource Centre for Consumer Participation in Health</td>
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<td>QaRNS</td>
<td>Quality Assurance Department, Royal North Shore</td>
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<td>ECV</td>
<td>External Cephalic Version</td>
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Chapter 1

INTRODUCTION

My professional career as a registered nurse and midwife spans more than 20 years. In this time I have worked in the public, private and community sectors of Australian healthcare, in metropolitan and rural settings. Throughout my career I have seen, heard and participated in numerous initiatives intended to improve the quality and safety of healthcare. Of significance to my present practice is the planning and delivery of healthcare and in particular why the collaborative or participative approach to healthcare planning seems both reasonable yet unachievable at the same time.

In my professional practice I have seen community links fostered through initiatives such as health councils; forums designed to facilitate collaboration between professionals and community representatives in the planning of health service delivery. I have engaged in numerous National and State endorsed strategies intended to enable healthcare consumers to participate in their healthcare. I have heard colleagues refer to healthcare recipients as consumers, rather than the traditional term of patient.

Recently, my interest has turned to determining the impact initiatives (such as those mentioned above) have had on my own practice, the practice of my professional colleagues, the individual healthcare consumer and the wider community. In 1998, I completed a research project in rural New South Wales (NSW) that explored the effectiveness of the antenatal record (a NSW Health endorsed interventions known as PNC2), and its impact on the universal concerns of maternity healthcare consumers, that being, continuity of care, safety and information sharing (Patterson & Logan-Sinclair 2003). In brief, the project identified that healthcare providers (n=15) rated the PNC2 as vital for planning maternity care, a primary source of information (100%), an effective communication tool (87%) and likely to positively effect continuity of maternity care received by the consumer (93%). In contrast, the consumer sample (n=42) viewed the PNC2 as primarily for the purposes of the provider
and 60% of the sample indicated that the PNC2 had no effect on the continuity of maternity care received (Patterson & Logan-Sinclair 2003). An interesting outcome of this project is that both the provider and consumer groups identified inconsistencies in the giving out and use of the PNC2, and that the PNC2 is mostly an incomplete document that is difficult to read (Patterson & Logan-Sinclair 2003).

The 1998 research project raised more questions than answers. The findings demonstrated a mismatch between the views of providers and consumers, it also identified that providers tend to rate a document that is both incomplete and illegible, as an effective communication tool or information source. The findings show that medical practitioners, known as the primary maternity care providers, are the least likely to comply with the NSW Department of Health Circular 94/73 and local organisational policy (Patterson & Logan-Sinclair 2003). It is argued that disregard for government or organisational policy is a self-righteous act, an arrogance associated with ‘traditional paternalistic medicine’, and a strategy that has proven to be effective in ‘delaying the introduction of models of maternity care that encroach on medical autonomy in the rural setting’ (Patterson & Logan-Sinclair 2003 p. 114). These findings however, do not suggest a demise of professional dominance in the planning and delivery of healthcare, or an ascendency of collaboration and community participation in healthcare. The findings from the 1998 research project are discussed further in the literature review.

The 1998 research project has been instrumental in my decision to seek opportunities to research consumer participation and its significance in the pursuit of healthcare quality and safety. How is consumer participation operationalised? What does it look like to providers and consumers? How is it communicated, specifically in a documented form? These are just a few of the questions that motivated me to engage in further research and in particular this study.
Study Background

This section outlines the background to this study. This study is essentially a reflection of my professional and personal journey; however, the fact that this study is also nested within a large Commonwealth project is significant on the design, interpretation and discussion of the study’s findings. The large project I referred to is funded by the Commonwealth Department of Health and Aged Care, New South Wales Department of Health, Queensland Health and the Victorian Department of Human Services. Professor Pieter Degeling is the project sponsor and I am a member of the Phase Two Commonwealth project team that is located within the Centre for Clinical Governance Research, School of Medicine, University of New South Wales.

To understand how this study interconnects with the Commonwealth project, this section will feature an outline of the Commonwealth project. Professor Pieter Degeling describes the Commonwealth project as:

A project to assess the impact of work process control structures and methods on technical efficiency, clinical integration, quality and clinical outcomes and of the factors, which influence their successful implementation (Degeling et al 1997)

It is anticipated by the Commonwealth funding bodies that the project will prove to be significant in implementing aspects of the Health Agreements that exist between the Commonwealth and the States. It is the aim of the Commonwealth project team to: improve the evidentiary basis of clinical practice and service delivery; extend the development and implementation of multidisciplinary clinical pathways in designing, delivering, assessing and benchmarking services; extend consumer involvement in designing, delivering and assessing service delivery and improving the continuity of care, its quality and cost effectiveness (Degeling et al 1997).

The intentions of the Commonwealth project are ambitious; consequently, the project is designed to be completed in two phases. Phase One, the pilot phase,
was completed in 1999 in New South Wales, and Phase Two saw the project extended into Queensland and Victoria, and commenced in 2000. The project’s design is a multi-method, triangulated approach, with the methods piloted in Phase One being refined and applied in Phase Two of the project.

The findings from Phase One were released in the 2000 report entitled; ‘The Organisation of Hospital Care and its Effects’ (Degeling et al 2000) and had two foci. Firstly, organisational context is determined by measuring each site’s propensity to control or standardise the way clinical work is organised and the management of related financial issues. Secondly, impact of care is determined by measuring the quality and composition of healthcare. Phase One included examining approaches to healthcare delivery, quality of care measures, and the cost for three homogeneous surgical procedures 1. appendicectomy, 2. transurethral prostatectomy (TURP) and, 3. elective caesarean section (ECS), in twelve clinical settings in public hospitals across New South Wales. Phase One’s multi-method approach included a medical record audit, an organisational audit, management and clinician surveys and interviews, and consumer surveys. The data from Phase One identified that sites with stringent budget management and standardised care processes tend to display lower variability and higher quality healthcare measures. One of the most significant findings for the project team, that influenced planning for Phase Two of the project, was that most sites are focused on meeting budget and activity targets and are unlikely to demonstrate interest in integrating or standardising the delivery of healthcare (i.e. clinical work).

Phase Two, ‘Systematising care in Elective Caesarean Section – controlling costs or quality?’ (Sorensen et al 2001) built on from Phase One, expanding into the states of Queensland and Victoria. Phase Two tests the proposition that clinical teams using work process control structures and methods, are clinical teams which: 1. had lower cost per patient episode of care; 2. had lower rates of clinical practice variation and; 3. had better quality and higher patient satisfaction measures.
Phase Two of the Commonwealth project targets clinical teams and the organisation of care related to the clinical condition, elective caesarean section (ECS). The findings from Phase One highlight that the organisation of clinical care for ECS is comparatively more systemised than the organisation of appendicectomy or TURP clinical care (Degeling et al. 2000). Furthermore, representatives from Queensland Health and The Victorian Department of Human Services also agree that ECS care tends to be more systematised in their states (Sorensen et al. 2001).

Dr Ros Sorensen led the Phase Two project team. My role in the project team has primary and secondary functions. Primary functions include being an expert on nursing/midwifery care related to ECS and being responsible for auditing the medical record samples for quality of clinical care indicators. Secondary functions include interviewing health professionals, coordinating clinician and consumer survey distribution, collection, analysis, and contributing to report writing and oral presentations.

Motivated by my interest in consumer participation in healthcare, I recognised an opportunity to enhance the Phase Two project team’s understanding of the relationship between the quality of healthcare (determined via a medical record audit) and patient satisfaction measures (determined via self-report survey), through investigating indicators that consumers are actually participating in the planning and delivery of healthcare. Using the Consumers’ Health Forum of Australia (cited in Bastian 1994) definition that real participation means that there is evidence to support that joint problem solving, joint decision making, and joint responsibility are attributes of the consumers’ healthcare experience, I approached the Phase Two project team, and argued that their aim of determining a quality outcome measure would be assisted by identifying indicators of individual consumer participation in healthcare and determining the level of consumer/provider partnership activity.

The proposal I presented to the Commonwealth project team, was that I would seek to determine the level of consumer involvement experienced by the Phase Two samples. To do this I proposed to collect data (additional to the Phase
Two project team’s data) for the purpose of determining evidence of real consumer participation. I also intended to contribute to, and draw from the Phase Two project team’s comprehensive databases. The proposal was positively received by the principal researcher and Director of the Research Centre, Professor Pieter Degeling. With his approval I submitted an application to the funding bodies to include this Masters Research study as an extension of the Queensland public hospital ethics and data management processes.

Study Proposal

As stated previously, I am interested in identifying indicators of consumer participation in the planning and delivery of healthcare (consumerism in healthcare) and the influence of such participation on the quality and safety of healthcare. In order to determine my study’s aim, I need to carefully consider what consumerism in healthcare is, define consumer participation, and, in the context of Australian healthcare, identify the reality of consumer participation. In turn, each of these considerations will be briefly addressed, followed by a statement outlining this study’s preliminary aim. The study’s aim and objectives will not be formalised until completion of the literature review (Chapter Two).

Consumerism and Health

A preliminary review of the literature identified that in Australia consumerism originated in the 1960s and was seen as a form of social rebellion (Marsden 1996). Consumerism was labelled a social protest, which is linked to the technological, economic and political changes that occurred in Western developed countries at that time. During the 1970-80s, consumerism became increasingly synonymous with representing the supposedly weaker individual; specifically those who challenged or protested against inequities, or defied exploitation by those considered more powerful, influential or in control of resources (Marsden 1996).
Having the capacity to intensify and diversify its identity as a force for change is recognised as one of the most influential attributes of the consumer movement. For example, in the 1980s, the Australian consumer movement followed the global consumerism trend by broadening its attention from product-centred issues to service related issues, such as healthcare. By broadening its focus, the consumer movement demonstrates its strategic propensity; that is, the covert recruitment of social and political groups with, or with a potential for, power and influence, whilst sustaining a public profile representative of mainstream middle class society (Marsden 1996).

With this capacity, scope and potential it is reasonable to assume, that in the 21st century, individual healthcare recipients and healthcare organisations would be influenced by the consumer movements’ philosophy in some way. The World Health Organisation (WHO), in the Declaration of Alma-Ata 1978: Primary Health Care supports, this assumption declaring that, ‘people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare’ (WHO 1978)

Considering this declaration is now over twenty years old and, the WHO is an international authority in healthcare reform, evidence of individual healthcare recipients participating actively should be easily identified in mainstream healthcare. In other words, in contemporary Australian healthcare settings, where patients are likely to be addressed as healthcare consumers, it is a reasonable aim of this study to explore whether individual participation in healthcare, is in fact, as contemporary as the title consumer suggests.

Defining Consumer Participation and Healthcare Consumers

In 1990, consumer participation is described by the Consumers’ Health Forum (CHF) of Australia publication, ‘Guidelines for consumer representatives: suggestions for consumer or community representatives working on public committees’ (cited in Bastian 1994) as:
... more sharing, not only of information and opinion, but also of decision making power. Real participation means joint problem solving, joint decision making, joint responsibility (p.4).

A decade later, the Commonwealth Department of Health and Aged Care in their publication, ‘Improving health services through consumer participation: a resource guide for organisations’ (Consumer Focus Collaboration 2000a), took a broader view of consumer participation, where responsibility ranges from the collective to the individual, and identify healthcare consumers as:

People whom directly or indirectly make use of health services....Consumers are as diverse as the full range of people living in contemporary Australian society (p 4).

With these definitions being over ten years old, it is reasonable to assume that consumer participation has had some impact on the planning and delivering of healthcare in Australia. In addition, with the responsibility for participation being broad, it is likely that consumer participation will be evident in organisational structures and philosophies, as well as the views and behaviours of health professionals and communities.

**Consumer Participation – The Australian Context**

To meaningfully understand consumer participation in the Australian healthcare context, there are some fundamental questions that need to be considered. Questions like: 1. what were the intentions of Australian healthcare organisations, at the policy level, in regard to facilitating individual consumer participation in healthcare? and, 2. how is that policy practiced at the frontline of healthcare? An awareness of these issues is required in order to determine this study’s aims therefore, a brief response to the questions follows.

It was in 1996, that the Australian Health Ministers’ Advisory Council (AHMAC) (1996) formalised consumer participation as a national priority. AHMAC recommended that healthcare facilities commit to reviewing and
redesigning service provision by: focusing on activating the level of consumer participation; developing healthcare partnerships; and generating consumer outcome measures. These are somewhat puzzling recommendations because the evidence available to healthcare organisations in 1996 that would allow them to effectively conceptualise and then implement consumer participation as a quality intervention was not easily accessible. The evidence that existed was described as of modest quantity and questionable quality (Consumer Focus Collaboration 2000b). This means that healthcare organisations were set the challenge to substantially reorient traditional methods of service provision and offer a customer service model. At the same time, these organisations were unfamiliar with factors that may potentially facilitate or obstruct implementation, or were unlikely to recognise the presence or outcomes of an active level of consumer participation in health related terms, even if it did occur.

Subsequently (and in my clinical experiences) consumer participation at the frontline of healthcare tends to be erratic or reactive, rather than integrated into service delivery philosophy and practice. Although this a problematic approach to implementing a consumer-oriented model of healthcare, it should not be unexpected, considering the limited availability of systematic scientific research methods capable of capturing, let alone validating, consumer participation measures. Equally problematic, is the absence of an audience receptive of healthcare’s struggle to adopt this model, with the political rhetoric that the adoption of the consumer participation philosophy into Australian healthcare organisations is well on the way to being achieved (The Australian Institute of Health and Welfare [AIHW] 2000) being the favoured headline.

The political rhetoric is further romanticised with assertions such as the projected benefits to the consumer, community and the healthcare organisation. These are acclaimed as being sufficient incentive to support facilitation, and therefore the practice, of real individual consumer participation in Australian healthcare settings (Consumer Focus Collaboration 2000a; Australian Council for Safety and Quality in Health Care ACSQHC
The incentives for change tend to be framed around social policy commitments such as promotion of the legal, ethical and democratic rights of individuals, as well as assurances that an improved and safer health service will be delivered.

Therefore, in determining the aim of this study, I am mindful of the gap between the rhetoric and reality of consumerism being an active force in Australian healthcare. This study is an opportunity to critically examine what consumer participation looks like in Australian healthcare settings. However, I am prepared for multiple interpretations of participation and indicators that policy is practice.

**Preliminary Study Aim**

Based on the aforementioned definitions and statements, the study’s preliminary aim is to determine indicators of consumer participation in the planning and delivery of healthcare in the Australian context. To accommodate my role in Phase Two of the Commonwealth project, the this study will focus on the surgical procedure, elective caesarean section (ECS), and the examination of the medical record contents as a means to retrospectively extrapolate factors that can be considered representative, or supportive, of consumer participation throughout the healthcare trajectory.

**Summary**

In this Chapter, my motivation for completing this study has been introduced. The fact that this study is an independent study nestled within a larger project has been detailed. The implications of being linked to a larger Commonwealth project team, being responsible for auditing medical records for quality indicators and having access to an extensive database has been referred to. Before stating the study’s preliminary aim, I presented a brief overview of some of the key issues related to consumerism, healthcare and reform in the Australian context. This overview highlights that apart from the study having
personal significance it will also contribute to an area of healthcare research that has up to now, been deficient.

Following Chapters

The following chapter reviews the published literature in relation to consumer participation in individual care, and in particular elective caesarean section. The methods of measuring participation outcomes and the role of the medical record will also be included. Chapter Three describes the methodology of the study, operationalising the study’s aims and objectives in the Queensland public hospital maternity care setting. Chapter Four details the analyses and treatment of the data, Chapter Five triangulates and discusses the significant findings, and Chapter Six summarises the implications and areas for further research that have arisen as a consequence of this study.
Chapter Two

LITERATURE REVIEW

Introduction

Determining indicators of consumer participation in the planning and delivery of healthcare, in an Australian context, has been described as the preliminary aim of this study. Consumer participation in healthcare has been introduced in Chapter One as being multi-faceted. To meaningfully understand the diversity of consumer participation in healthcare in the context of this study, the literature review has been divided into five sections. In addition, with the study being set in the public hospital maternity healthcare service of Queensland, Australia, the key stakeholders associated with elective caesarean section healthcare will also feature prominently throughout the review. The NHMRC (1996) state these stakeholders to be:

- women; the primary healthcare consumer or
- midwives and doctors; as the primary healthcare providers

The first section of the review details some of the organisational and social influences within healthcare. The focus is the rhetoric associated with consumer participation in healthcare. The review presents the organisational structures that define consumer roles in the study sites. It should be noted that the literature within the first section tends to be limited and descriptive in nature; however, an understanding of the literature is imperative for the purpose of future reference and debate.

The second section provides an overview of the consumer participation in individual healthcare philosophy. Arguments supporting the principles of individual healthcare participation and the increasing participation profile debated in national and international forums are presented. Individual participation is divided into the components of decision making and information sharing. The negotiation and implementation of these practice
principles in the generic healthcare relationship is the crucial component of this section of the literature review.

The third section aims to link the broad operational and philosophical principles presented in the first and second section to the study's specific focus. Consumer participation is initially reviewed within the context of the generic maternity care setting followed by a review targeting participation and elective caesarean section literature. Finally, individual participation is critically examined within the context of the decision making and information sharing elements of the healthcare relationship.

With an understanding of the dimensions of consumer participation and the qualities of a participative healthcare relationship on an individual level, the fourth section reviews methods of measuring these qualities, commonly expressed in healthcare terminology as outcomes. Defining measurable outcomes of consumer participation in healthcare, on an organisational and individual level, is pertinent before reviewing the methods employed to measure outcomes. Consequently, this section is designed to reflect this sequence.

The fifth and final section reviews the role of the medical record in the overall healthcare experience. Documentation as a form of social, professional and organisational communication and issues related to access, legibility, completeness and legal requirements are explored. Examples of the medical record’s content being applied in research as a means to determine healthcare quality and review clinical practice are examined. Methods of improving the validity and reliability of the medical record’s data will also be detailed.

The literature review concludes with a comprehensive summary, drawing together the significant findings, discussion points, and highlights of each of the five sections. In consideration of the literature, the study's aims and objectives will be legitimised, leading into the methodology in Chapter Three.
Section One: The Context – Consumer Participation in Healthcare

Before examining the specific or micro details of consumer participation in individual healthcare literature, it is pertinent to initially examine the generic, or macro concepts, relating to the organisational and social conditions in which this study is set.

Queensland Health and Consumer Participation

In September 2000, Queensland Health pledged commitment to the principles of consumer collaboration in their Health Service Integration Position Statement and their Strategic Plan for Quality, Quality Improvement and Enhancement Program: 1999-2004. This commitment was in accordance with International and Commonwealth recommendations that endorse enhancing consumer participation in their own healthcare and taking a broader role within healthcare systems (Alma-Ata Declaration 1978; National Health Strategies 1993; National Expert Advisory Group1999).

Queensland Health had quality goals attached to their pledged commitment (<www.health.qld.gov.au/quality/strategic.htm>) and it was predicted that there would be standardised models of, and minimum standards for, consumer participation by 2003. Queensland Health also aims to implement a state-wide standardised patient complaint and feedback/survey system to facilitate data utilisation and benchmarking.

Prior to publication of their quality plan, Queensland Health is not unlike other Australian states and territories, in that consumer participation is not integrated as a dimension of healthcare quality. Indeed there is an absence of commitment to formal policy regulating consumer participation and limitations exist in generating reliable and consistent data sets (AIHW 2000).

In the global context, determining or measuring any form of healthcare quality is a world-wide phenomenon (Lovern 2000). In the context of hospital standards and accreditation, Australia is considered an early adopter of
accreditation processes. The awarding of accreditation status is highly sought by Australian healthcare organisations and such status is viewed as a reflection of high quality healthcare service. In 2000, The Australian Council on Healthcare Standards (ACHS) EQuIP program was the most often used accreditation system (AIHW 2002). In Australia's twenty-five year accreditation history, the method of determining accreditation status has changed continuously; there have been thirteen editions of the previous Accreditation Guide and the EQuIP program is now in its third edition. The current version of the EQuIP program is claimed by the ACHS to be a holistic accreditation process that focuses on continuous improvement.

Significantly, in spite of continuous improvements in the process of determining healthcare quality, consumer participation does not feature in the ACHS accreditation process. In fact there is minimal reference to consumer outcome measures or evidence to support that the accreditation process impacts on the consumers' healthcare experiences, let alone the quality of healthcare (Fairbrother & Gleeson 2000; Roth & Taleff 2002). The AIHW openly criticise the ACHS accreditation process for its limited capacity to generate a reliable source of quality data, owing to the processes being left to the discretion of individual healthcare facilities and area health services; a process that is neither mandatory, nor standardised. The AIHW criticism gives credence to questioning the reliability of other statements, such as that made by the Steering Committee for the Review of Commonwealth/State Service Provision (SCRCSSP cited in AIHW 2000) that nationally, consumers tend to be highly satisfied with care provided in acute care hospitals.

In relation to Queensland Health's commitment to the principles of consumer collaboration, the literature suggests that anecdotally there is a logical relationship between healthcare quality in an organisational context and consumer participation (or satisfaction) in healthcare, and many stakeholders believe this to be true (Rawlins 2001; Sheahan 1999). The literature also suggests that this belief is merely conjecture, because of the scarcity of national information that can be collated or reported on (AIHW 2000; ACSQHC 2000a). Therefore, the literature supports Queensland Health's
intention of standardising and setting standards for consumer participation. The literature also indicates that access to empirical evidence to model and validate any consumer participation standards, may not be reliable or even available at this time.

**Challenging Tradition – Public Hospitals and Social Roles**

Public hospitals in Australia are generally described as large complex institutions capable of performing a wide variety of health related activities. The AIHW (2000) reports that over the past decade the Australian hospital system has been challenged by rising healthcare costs, reducing budgets, and pressures to provide equity and access to quality healthcare services. Parallel to this, the traditional hospital social system has also been challenged, one that was dependent on individuals seeking healthcare and relinquishing control of virtually every aspect of their lives, taking on the *sick* or *patient* role, a role that required them to conform, cooperate, and not interrupt routine (Irvine 1999).

In 1994, Bishop described the interactions of the recipients and providers of healthcare as *mini-dramas*, where behaviours are strictly governed by socially prescribed roles and structures. In the 21st century, the interpretation of healthcare roles and services has been confronted by globalisation and the high profile of consumerism in the public media. It is interesting that the increasing impact of these changes on the functional aspects of service delivery are often and openly debated, whilst its impact on the traditional social systems of healthcare are not well published.

In the social system of healthcare, tradition takes many forms. When challenging tradition, one is challenging the collective attitudes, opinions, beliefs, habits and customs that have been handed down from generation to generation within a given society (Madjar 1992). An example of the traditional recipient/provider relationship is where the healthcare recipient’s sick role is legitimised by the provider, and the recipient adopts the dependent and submissive *patient* role, willingly surrendering his/her decision making
contribution to the knowledgeable medical expert (Irvine 1999). It is when the interactions described above are internalised by the social systems of a society, within its beliefs, education and attitudes, that medical hegemony exists (Crookes 1992).

In response to the rising challenge to reorientate not only the delivery of traditional healthcare services but also the social systems, Australian public hospitals are adopting a patient centred care model or shared responsibility structure (ACSQHC 2000). In this model the healthcare provider functions within a multidisciplinary team and the healthcare recipient is regarded as an autonomous health service consumer (Berglund 1998). The patient’s role, as in the consumer oriented philosophy of equal partners with different expertise approach to healthcare decision making, is to be an active participant, sharing the responsibility of healthcare decision making (Coulter & Dunn 2002). An emergent issue relevant to this study is that in challenging medical hegemony, you are challenging social hierarchy that underpins the belief structures of many Australian communities.

The healthcare literature that has been reviewed tends not to focus on, or overtly appreciate the impact of challenging traditional healthcare beliefs, attitudes, or social roles. In essence, very little attention is paid to reporting on the nature, characteristics, or effects, of social renegotiation; even though it can be assumed that the successful reorientation of service delivery from medical hegemony to a shared responsibility structure would be dependent on the simultaneous transition of the healthcare recipient/provider relationship.

Consumer Oriented Model of Healthcare

Contemporary consumer-oriented healthcare models have been designed to focus on the healthcare recipient or consumer; incorporating systems that recognised the consumer/community needs, or at least the needs of consumers as seen by professionals. This is in contrast to traditional healthcare, where hegemony was modelled and the primary function was to accommodate the needs of healthcare providers.
The above approach suggests a social trend towards the individual recipient adopting a service–user or consumer ethos to healthcare. This purports the view of patients as consumers who are less likely to blindly accept healthcare providers as being all knowing on matters pertaining to their healthcare. Patient-centred care can seem to be an all encompassing title, yet what does it mean? Mead & Bower (2000) describe patient-centred care as: understanding the patient; acknowledging the patient’s prior experiences; seeing illness through the patient’s eyes; giving information; patient involvement in decision making; and, being responsive to patients’ wants, needs and preferences. These attributes are thought to generate a collective responsibility for healthcare, assisting the patient to transition towards a more active consumer role in healthcare; therefore, enhancing the quality and safety of healthcare, as well as satisfaction with the service provided (ACSQHC 2000b).

Reorientation and the Healthcare Provider

Reorientation of healthcare processes and systems towards a stronger consumer focus is a recommendation of the Quality in Australian Healthcare Taskforce (1996). This recommendation is credited with being the most likely to impact on service safety and service quality by dramatically minimising preventable adverse health outcomes. McMillan (2001) in her editorial comments agrees that healthcare reorientation is overdue. Referencing the taskforces recommendations, McMillan suggests that such complex changes should not be contemplated without considering and including individual healthcare providers, in particular frontline clinicians. McMillan (2001) claims that attempts to reorient service delivery towards the consumer focused model have been obstructed by unwarranted expectations being placed on healthcare providers. It is assumed that providers are; knowledgeable of contemporary healthcare practices; willing to collaborate; and have the capacity to reconceptualize and reorganise their existing clinical practices. McMillan claims that social system reorientation is not on the agenda or a priority of the individual healthcare provider (2001).
McMillan (2001) argues that in healthcare, when planning to implement change such as a reorientation of the service delivery model, fundamental issues are often neglected. This results in the proposed change being perfunctory, with healthcare providers being conditioned into modelling *token* changes in the delivery of healthcare. This is a learned behaviour, and can be accounted for by recurring events such as the systemic lack of coordination, consensus and consistency in the interpretation and integration of participation (change) strategies in service delivery. McMillan associates health professionals' apparent lack of motivation or cynicism regarding the incorporation of participation principles in their practices, not as a reflection of how they view the principles of consumer participation, but as a result of numerous haphazard attempts to remodel the healthcare system overall (2001). This suggestion indicates that an individual’s behaviours reflect the service’s limited capacity to manage change and is significant to this study. An emerging issue from this discussion and a key issue in the context of this study is that to identify participation at the individual consumer level requires identifying the capacity of both the individual, and the service, to facilitate or value social system reorientation.

McMillan’s assertions imply that although the consumer oriented model may be a contemporary approach to healthcare, the implementation (or lack thereof) is far from contemporary. It must also be acknowledged that McMillan’s comments are also representative of many of the published and unpublished consumer–oriented healthcare literature, in that they rely heavily on self reports and anecdotal evidence.

The implementation of change within the context of healthcare, such as service delivery reorientation, appears to be notorious for its lack of coordination, monitoring or evaluation linked to the change process. An example provided by Johnson and Silburn (2000), who completed an Australian wide consumer participation process *snapshot*, identified that the commitment of healthcare organisations was primarily directed at the management level, with the purpose of developing consumer oriented projects and policies. It did not matter whether consumer participation was approached
on a community or individual level; organisations were generally uncoordinated, fragmented, with ad hoc activities that had little impact. Ironically, the sixty-four health services across Australia that volunteered to participate in the semi-structured telephone interview were specifically invited to participate in the study because they were considered representative of those services that had a local reputation for undertaking work in consumer participation.

Johnson and Silburn’s (2000) snapshot supports McMillan’s (2001) criticism of the contemporary healthcare service preferring traditional change strategies. For example, from the services that were actively undertaking service reorientation strategies, there was minimal consideration given to developing infrastructure that would support or sustain reorientation at the frontline of care, such the involvement of all stakeholders in project planning or staff development and consumer training programs. Johnson and Silburn’s (2000) snapshot is only a consideration of the organisations’ commitment to, not the recipient/provider impact of, consumer participation. This approach is another example of alienating the social and service aspects of reorientation.

Reorientation and the Community

Another dimension to consumer participation is the responsiveness or readiness of the community or the individual consumer to reorientate towards such models. Some of the concepts that have to be considered include the diversity of the lives, views, values and healthcare needs of the community likely to be influenced by the reorientation. The usefulness of the consumer-oriented healthcare model to the community is also dependent on the individual or representative consumers. They require the capacity and ability to communicate their expectations and needs into priorities, which can then be translated into healthcare practices and resources. The community’s responsiveness to such models is also reliant on the context of the healthcare environment. The findings of a survey that sought healthcare providers’ attitude to consumers’ requests for elective surgery (Paterson-Brown 1998) suggests that over the last ten years the context of the healthcare environment
has shifted towards being more responsive to consumer choice and views, rather than judgemental or dictatorial.

Acculturation of the Consumer Model

Acculturation has been described as the process, whereby two different cultural groups have sustained contact and those individuals whose primary experiences have been in one culture, adopt the identity, attitudes, values and behaviours of the other culture (Rissel 1997). However, it should not be assumed that changes in the minority culture take place uniformly. Individuals within a particular population (and even within a family or profession) are likely to display varying degrees of acculturation to the dominant culture. Sim et al (cited in Rissel 1997) argues that these variations may also be the potential source of conflict and stress for individuals.

In the context of this literature review, a desired outcome of contemporary healthcare reorientation strategies would be the acculturation of the consumer-oriented approach in preference to the medical model of healthcare. Acculturation appears to be a process of social renegotiation, letting go and taking up. Rob Irvine’s (1999) chapter in Health in Australia: sociological concepts, stood out in the literature reviewed for its discussion of healthcare, consumerism, power and socio-cultural change. Irvine supports Rissel’s (1997) predictions of the individual struggling for a common purpose or identity, and relates this to healthcare and the recipient/provider role relationship. Irvine sets a convincing argument that in attempting to align the competing concerns between individuals, specifically in regard to beliefs and values associated with healthcare, it is likely to result in escalating distress and isolation rather than a common identity (1999). Rather than facilitating acculturation, this is likely to obstruct the process; therefore, sustaining dissonance and thus disempowering the community. Poignantly, Irvine (1999) also debates whether aiming for collective consciousness within a community is in fact to the benefit or the detriment of the consumer-oriented healthcare philosophy, or whether is it in fact benefiting those who oppose the philosophy. Perhaps even, another form of hegemony.
Hence, if acculturation or collective consciousness is to prevail, cultural consensus must exist across the population. This presupposes that a disruption or reorientation to the existing social order must ensue. Based on the literature reviewed, such a disruption would be dependent on: the ability of healthcare services to absorb and support the diverse needs and expectations of the community; the capacity of healthcare providers to reconceptualize their practice; and, uniformity in the individual’s perceived and communicated needs. In addition, it is difficult to ascertain from the literature, whether it is the healthcare service, provider or community, which is the minority culture.

The key issue that has emerged from this review of the literature is that a participative approach is a model not a mould. An ideal starting point for a reorientation of healthcare service delivery and social systems would be to equally value and tolerate each stakeholder and acknowledge common ground. However, the simplicity of this approach belies the complexity of healthcare.

**Maternity Services and Consumer Models of Healthcare**

Australian women, as consumers of maternity services, are claimed to be one of the most comprehensively reviewed consumer groups within Australia. Maternity service reviews include the 'Shearman Report', 1989, 'Having a Baby in Victoria', 1990, 'Western Australian Report on Obstetric, Neonatal & Gynaecological Services', 1990, 'Options For Effective Care in Childbirth', 1996 and 'Rocking the Cradle Report' 1999. Although the claims and reviews may appear impressive, examining the reports for issues related to the aims of this study has identified that maternity service reviews are predominantly just that; service reviews.

The fact that the scope of the service reviews is not adequately addressing individual participation in healthcare was also identified by the National Health & Medical Research Council (NHMRC 1996). The NHMRC (1996) recommends that Australian maternity services implement strategies to identify and address consumer issues rather than political issues; the aim being to improve maternity service provision, satisfaction and healthcare quality. As a starting point for reorienting maternity service provision, the NHMRC (1996)
advocates a sharing of power and responsibility within the consumer/provider relationship; that is, the women-centred care model. This model requires a shift from co-operation–guidance to a mutual participation model (Mead & Bower 2000). It was envisaged that the women-centred model would provide women with opportunities to exercise their personal and collective autonomy, incorporating expanded options and choices in publicly available services (Irvine 1999).

The NHMRC (1996) also states that the implementation of strategies to support reorientation of healthcare service delivery and social systems is more than gaining women’s satisfaction with their care. It is a commitment to facilitating the consumer/provider relationship, that is determined by the support and commitment demonstrated by the maternity service, healthcare providers and the community it serves.

To their credit, Australian maternity services were quick to respond and change the label of their approach to healthcare. They were considered pioneers in the adoption of the consumer-oriented model. Despite this commendable response, it is noted in the current Commonwealth Maternity Services Review, ‘Rocking the Cradle; A report into Childbirth Procedures’ (1999), that governments, services and professional groups have failed to act upon not only the NHMRC (1996) recommendations, but also recommendations that date back to 1989. The concept of un-informed consent, unequal power relationships, and absence of informing women of adverse consequences related to medical procedures and interventions, are just a few of the issues raised in the 1999 Senate report. Specific recommendations include ensuring the provision of timely, comprehensive, accurate and objective information related to antenatal and birth options. In order to address the absence of significant consumer input in service delivery and practice guidelines, the Senate (1999) also recommends an inclusive approach that considers the patients’ preferences and values, clinicians’ values and experience, and the availability of service resources.
In the literature and reports reviewed, it is common practice for Australian maternity services to self report commitment to implementing the above recommendations and to involving consumers in care planning; therefore, providing options and choices for women and their families. However, a recent assessment of New South Wales maternity services reports that service based initiatives, which intend to provide women with healthcare options, do not reflect commitment from healthcare professionals to restructure their services and redefine their professional practice (NSW Health 2000). Considering the Senate (1999) report’s similar findings, it can be suggested that the maternity services’ rhetoric of reorientation towards a consumer-oriented model cannot be justified.

Obstacles to Operationalising Consumer Models in a Maternity Service

Now, more than two decades on from the 1978 Declaration of Alma Ata, the reorientation of healthcare models, to be consumer focused or to provide options appropriate for the individual/collective consumer, is on the agenda and within the mission statement of most health services; however, the operationalising of the reorientation agenda continues to evade service delivery. Within the healthcare literature, some of the obstacles particular to maternity services operationalising the consumer oriented model, have been summarised to include: variances between what the consumer and the provider determine to be healthcare quality (Proctor 1998); the selective appointment and manipulation of healthcare consumer representatives (Bastian1994); professional paternalism and territorial preoccupation between healthcare providers (Woodward 1998); and, insufficient knowledge or access to evidence based or best practice principles by providers at the frontline of healthcare (Wagner 2000).

In relation to the community’s expectations of maternity services, in particular women’s participation in maternity care, obstacles are linked to a diverse range of factors including; women’s perceptions of service access; attitudes; orientation; and, the individual and collective woman’s circumstances and needs (Drummond & Rickwood 1997; Lowe 1991; Enkin et al. 1995; Czarnocka
& Slade 2000). Hence, in spite of numerous and high profile service reviews, the barriers to reorientation within a maternity care setting are not dissimilar to the generic service, provider and consumer issues discussed previously. Furthermore, the literature also supports the tendency for self reported or anecdotal claims of commitment to a philosophy, which is unsubstantiated.

**Section One Summary**

This section provides a broad overview of organisational and social structures that influence the context of consumer participation in healthcare settings. The literature, although predominantly descriptive, suggests that rather than taking the healthcare model to another dimension, consumer participation in healthcare is simply a service commitment (lip service) that is not representative of service delivery.

Key points from the literature include:-

- Access to empirical evidence to model and validate consumer participation standards may not be reliable or even available at this time.

- Very little attention is being paid to reporting on the nature, characteristics or effects of any renegotiation of the social structure of healthcare. Even though reorientation of service delivery is dependent on such change.

- A participative approach, that equally values and tolerates each stakeholder, acknowledging ‘common ground’, is an ideal starting point for the reorientation of healthcare service delivery and social systems. The simplicity of this approach belies the complexity of healthcare.

- The successful implementation of strategies to support reorientation of healthcare service delivery and social systems is more than gaining consumer satisfaction with their care.
Barriers to reorientation within a maternity care setting are not dissimilar to the generic health service, provider and consumer issues.

The literature implies a lack of initiative in undertaking the consumer focussed approach to healthcare. Traditional **top-down** methods of change management have been shown to have minimal impact on the service, provider or community/consumer. The need for key stakeholders to confront their respective cultures, beliefs, and values, with the intention of reconceptualising, negotiating and moving in the direction of consumer focused healthcare has not been pursued.

One contradiction that emerged from the literature was that the State and National healthcare bodies tend on one hand to promote their commitment to, and the success of, interventions to integrate consumer oriented healthcare models, whilst on the other hand claim that a lack of quality data or measurement standards limits their capacity to substantiate any outcomes associated with their claimed successes. In spite of these shortcomings, the consumer participation dimension of quality in public healthcare, including maternity and acute care settings, continues to endorse the organisational rhetoric that consumer satisfaction is high and healthcare relationships are participative and collaborative.

The literature review will now examine the consumer participation literature in regard to practicing the philosophy of consumer participation in the healthcare context and the specific elements of information sharing and decision making in individual healthcare.
Section Two: Practicing the Philosophy

The philosophy of consumer participation in healthcare reflects a social model of health, a model that focuses on enabling and empowering individuals to take responsibility and participate in aspects that impact on their health. This is detailed in the 1978 WHO Declaration of Alma-Ata and the 1986 Ottawa Charter for Health Promotion (Boddy 1992).

The context of consumer participation in Australian healthcare settings has been examined in the first section of the literature review. The progressive reorientation of health services towards the consumer oriented model is the rhetoric that is accepted and expected; despite limited evidence or infrastructure to support service philosophy or delivery restructure. Health is examined as a complex social model, and any reorientation requires careful consideration of the attributes and attitudes of individuals and communities that are required to function within such a model. The practice of the participation philosophy will be examined and the elements of healthcare information sharing and decision making will be critiqued.

Evidence Supporting Consumer Participation in Individual Care

The Consumer Focus Collaboration (CFC) was established in Australia in 1997 and has National representation, including consumer and professional organisations, and Commonwealth, State and Territory health departments. The CFC’s terms of reference state that their overarching aim is one of, ‘fostering an active partnership between healthcare consumers and those who provide healthcare’ (CFC 2000c).

Past research undertaken on the participation of healthcare consumers or their representatives in service level processes, such as management boards or advisory groups, has been mostly focussed on describing or mapping current practice, understanding different participation methods and the barriers and enablers of participation strategies from the perspective of different stakeholders (CFC 2000c; Johnson & Silburn 2000; Draper 1997). To gain an
understanding of how consumer participation may look at the individual level, rather than the system wide level, the CFC undertook a comprehensive literature review. The CFC publication, ‘The Evidence Supporting Consumer Participation in Health’ (2001), outlines the core activities that they identified as facilitators of active consumer participation at the individual level of care:

Active consumer participation in decision making in individual care leads to improvements in health outcomes, and access to quality information facilitates decision making and supports an active role for consumers in managing their own health (p3).

In endorsing the above statement, the CFC alerts the reader, that although the evidence was compelling for the value of consumer participation in healthcare at the individual level, the supporting literature was scant and the methodologies used were self-limiting. These limitations prevented the CFC’s expert panel from meaningfully assessing the strength, size of effect and relevance of the supporting literatures design, analysis and outcomes. The scarcity of publications also impacted on the literature able to be reviewed for the purposes of this study.

Consumer Participation a National Priority Area

Recognising the work of the CFC and other working parties, the Australian Council for Safety and Quality in Healthcare (ACSQH) acknowledged the significance of consumer participation in healthcare by naming it as an individual priority area in their ‘National Action Plan 2001’. It is noteworthy that ACSQH recognised consumer participation principles to be a missing component, which needed to be addressed across all its priority areas. ACSQH (2000) endorsed the facilitation of participation through promoting healthcare consumer/provider partnerships at an individual level.

ACSQH’s (2000) recommendations were also stated to be confined by the absence of quality evidence, just as the CFC’s (2001) literature review concluded. In particular, ACSQH lacked the evidence that could clearly
articulate the relationship between consumer participation at the individual partnership level, and the safety and quality of healthcare. The inability to complete a systematic review of the scientific research related to consumer participation at the individual level, meant that the fundamental requirements for preparing best-practice guidelines, as set down by the NHMRC (2000), could not be met. As a result, the ACSQH was limited in their endorsement of standards or benchmarks for which health services could set goals to achieve. Significant to this study, both the CFC and ACSQH identify consumer participation at the individual level as an area that requires further attention.

ACSQH has encouraged research to be undertaken that could provide mechanisms to measure the impact and effectiveness of their recommendations. This study provides useful evidence for this purpose.

Consumer Participation and Healthcare Quality and Safety Inquiries

The Bristol Inquiry, an inquiry into the performance of surgeons involved in heart surgery on children at the Bristol Royal Infirmary between 1984 and 1995, highlights the potential for adverse outcomes and medical errors when health services and providers distance themselves from the individual recipients of the healthcare service, the consumer. The linking theme of the Bristol inquiry’s 198 recommendations for improving the safety and quality of healthcare, was that future consumer/provider healthcare relationships should be as equals with different expertise, based on the consumers being treated as partners by healthcare providers (Coulter & Dunn 2002).

The inquiry identified that despite the United Kingdom setting the goal of improving responsiveness to patients for several decades, most initiatives have failed to noticeably change the everyday experience of most healthcare consumers. It is evident that the reports’ recommendations to explore and build in transparency in the healthcare services and the providers’ progress in reorienting to a consumer focused model are urgent. However, the practicalities of planning, implementing, measuring and monitoring this reorientation were less evident.
Sponsorship of healthcare partnership at the individual level is a rhetoric that is well documented in healthcare. The Bristol Inquiry identified that partnership was not a reality in Bristol, and implied that it is not in fact a reality in numerous other healthcare services in the UK (Coulter & Dunn 2002). The significance of this study is that it explores the reality of this rhetoric within an Australian context.

Limitations of Scientific Methodologies for Social Research

The determination of factors that motivate healthcare professionals to reflect on and change their clinical practices and social behaviours has been following a similar trajectory to consumer participation research. The study most often associated with this line of research is Greco and Eisenberg's (1994) literature review of interventions aimed at changing physicians’ practices. They found that no one single method of intervention was inherently effective and that behaviour change was dependent on a participative approach and access to rigorously peer evaluated evidence.

In 1994, the Cochrane Effective Practice and Organisation of Care Group (EPOC) was formed. The intention of the Cochrane organisation was the creation and dissemination of predominantly scientific research findings. In activating this group, the EPOC reviewers (who were predominantly scientific researchers) were confronted with the reality that, ‘few, if any, studies were similar enough to make it appropriate to combine the results statistically’ (Bero et al. 2002). It was increasingly apparent that either the existing body of literature was not credible as it lacked the scientific rigour, or that applying a pure scientific approach was not reasonable for social research, such as behaviour change.

Likewise, reviewers of the consumer participation literature (CFC 2001; ACSQH 2000) have also struggled to apply a scientific methodology, with the literature dominated by authoritative opinions and evaluation of established practices in the absence of validated consumer participation research findings. This conundrum could explain why healthcare practices have not, or have been
very slow to change; as the clinicians could not access the evidence to quantifiably substantiate the effect of an intervention. This may appear laughable; however, it is also plausible.

This literature review highlights that three large collaborations (EPOC; CFC; ACSQH) have experienced difficulties determining the credibility of the existing literature using scientific criteria as the benchmark. This suggests that there is a place for descriptive, exploratory, qualitative, and quantitative approaches when exploring social paradigms such as healthcare behaviour change. Consequently, this study applies a triangulated methodology blending the social and the scientific aspects of healthcare research.

Summary - Evidence Supporting Consumer Participation in Individual Care

Consumer oriented healthcare is a social model of health focusing on enabling and empowering individuals to take responsibility and participate in aspects that impact on their health. Despite consumer participation being a frontline activity, dealing with individuals, the level of inquiry into such a model has predominantly centred on healthcare systems and service delivery.

Evidence supporting consumer participation at the individual level has been sought by numerous well resourced experts. Each review of the literature has resulted in similar findings and recommendations. The review findings are unanimous in the potential for consumer participation at the individual level to have significant influence in the quality and safety of healthcare. However, the literature is scarce, lacks scientific rigour and is predominantly opinion based or descriptive. The recommendations include undertaking quality consumer participation research.

Key issues related to this study from the literature include:-

- The CFC, ACSQH, and Bristol Inquiry have identified that consumer participation at the individual level is a priority area, closely linked to the quality and safety of healthcare.
An absence of credible/reliable methods to determine the presence, impact and effectiveness of consumer participation at the individual level. The significance of this study is that it provides useful evidence for this purpose in an Australian context.

There is a place for the descriptive, exploratory, qualitative, and quantitative approaches when exploring social issues such as healthcare behaviour change, whether it is the service, provider or consumer’s behaviour; consequently, this study applies a triangulated methodology, which blends the social and scientific aspects of healthcare research.

It would appear that public, political and professional groups have identified active consumer participation in individual care as an influential factor in healthcare quality and safety. Consumer participation in individual care or partnership was reported to be facilitated by access to quality information and participation in decision making. The literature on these two components will now be reviewed.

**The Practice of Information Sharing and Decision Making in Healthcare**

As stated earlier the CFC (2001) literature review asserts that access to quality information and participation in decision making are core attributes of consumer participation at the individual level of healthcare. Evidence of these attributes is associated with positive outcomes for the individual recipient (who will be identified as the consumer), the provider and the service. A brief overview of the consumer/provider relationship will precede an exploration of the factors that both inhibit and facilitate this relationship.

The consumer/provider relationship commonly centres on information sharing and decision making about treatment. There are many variations as to how this relationship is approached. Three approaches reoccur in the literature: paternalism, informed choice and shared decision making. Charles, Whelan and Gafni (1999) have deconstructed these approaches into characteristics and analytical steps (Figure 2.1).
In reference to Charles et al’s (1999) decision making spectrum, when a paternalistic approach to decision making is taken, the provider takes principal responsibility for decision making. With the informed choice approach, the consumer is provided with information and takes principal responsibility for the decision making. The shared decision making approach is the middle ground between the two; where the consumer and provider collaborate within each step. Shared decision making, also known as partnership in decision making, has been described as sharing the responsibility and sharing the uncertainty of healthcare decisions (Elwyn et al 1999). This relationship is characterised by valuing each participant’s expertise. For example, the provider is the expert in relation to diagnostic techniques, disease, prognosis, treatment and preventative strategies, whilst the consumer is the expert about
their experience of the illness, their social circumstances, and attitudes to risk, values and preferences (Coulter & Dunn 2002).

In the reality of healthcare, Charles et al (1999) suggest that it is likely that consumer/provider relationships will reflect some form of hybrid model. However, this is irrelevant in the consumer oriented healthcare model as it is the concept of valuing both the expertise of the provider and the consumer that is significant.

Healthcare Providers as Partners

Healthcare providers’ attitudes, particularly those of doctors, are often described as paternalistic in preference to partner oriented in their approach to healthcare decision making (Coulter 1999). In discussing case studies related to end-of-life issues, Glare and Tobin (2002) comment that the provider’s ability to choose what treatment options to offer was fundamental to the tradition of medicine. Healthcare providers have also commented that facilitating greater participation by the consumer in healthcare decisions has had an impact on the effectiveness of a traditional stress-minimising mechanism, where the provider distanced themselves from the consumer (England & Evans 1992). With greater participation by the consumer, the reduction in the provider’s decision making power has also been found to have had an undermining effect on self-image and perceived job satisfaction of the provider (England & Evans 1992).

It appears that healthcare providers attach considerable value to the responsibility of healthcare decision making and it is unlikely that they are going too willingly give-up something so valued because they were told to. As was discussed earlier in this review, the traditional top-down approach to change management is the usual practice. Furthermore, only token adoption of consumer participation principles is likely to be expressed, if strategies are not explored to seek the engagement, collaboration and cooperation of the providers.
An example of change strategy is the process of peer review. A recent peer review of Australasian medical schools curriculum, specifically the ethical components, reports that the traditional institutional medical practices that feature in the curriculum are outdated (ATEAM 2001). Furthermore, the authors, in their position statement, recommend that contemporary medical professional attitudes and behaviours be enacted within an ethical awareness and with moral reasoning, along with an understanding of the attitude, knowledge and skills required to negotiate autonomy, individual rights and paternalism in the consumer/doctor relationship.

The Decision Making Relationship

In undertaking a literature review to guide the development of competencies for the practice of shared decision making by healthcare providers, Towle & Godolphin (1999) initially identified barriers to consumer/doctor shared decision making. They found that the barriers predominantly originate from the healthcare provider feeling threatened due to a lack of knowledge, skill or time to develop a partnership relationship. Barriers influencing consumers include a perceived inexperience or reluctance in undertaking such a role (Towle & Godolphin 1999). This supports Bastian’s (2000) assertion that the focal point in balancing the decision making relationship should centre on the acknowledgement of the values, skills and knowledge of each individual in the partnership.

In examining the responses to a survey designed to determine an individuals’ (n=162) attitude to commonly promoted medical interventions, it was identified by Fitzgerald & Phillipov (2000) that health outcomes for the consumer and provider may be qualified and processed in conflicting contexts. In this situation, consumers’ views on the risk-benefit ratio of the interventions presented to them when making decisions varied from providers’ interpretations of risk and definition of acceptable outcomes. The difference in attitude was not related to the consumer not understanding the information presented. Fitzgerald & Phillipov (2000) do advise readers that it would be difficult to generalise their study findings external from the sample, and if the
implementation of best-practice guidelines for medical interventions is desired, it is best not to increase the consumer’s role in the decision making process.

Fitzgerald & Phillipov’s (2000) findings champion the earlier debate on whether collective consciousness is a realistic goal in relation to consumer participation. Wolf (1985) argues in his text on Clinical Decision Making in Physical Therapy that for improvements in the decision making processes, standardised practices are not the complete solution. He claims that it is the reliance on tradition, habit or convenience that narrows the decision making process. It is worthwhile to remember that decision making is an interactive process that might fluctuate over time and in different situations, a process that is rationally responsive to the needs, preferences and characteristics of the individual (Hibbard & Jewett 1996).

Influential Consumer Variables

A summary of the factors identified in the literature that influence consumer participation in healthcare at the individual level include: level of education and income (Mezey et al. 2000); culture and beliefs (Irvine et al. 2002); ability to express assertive and empowered behaviours (Schulman 1979; Bottles 2000); responses to stress and innate coping mechanisms (Rankin 2001); and, perceived control over events (England & Evans 1992). From the variables presented, there is no obvious reason why consumers should not be provided with the opportunity to participate in decisions related to their healthcare. In this context, participation is a voluntary choice, and can only be optimised by a consumer/provider relationship that acknowledges the variables that may influence the consumers’ interpretations of the situation and, eventually, their choices.

Preparatory Factors that Facilitate Participation

The literature suggests that shared decision making in the context of the current healthcare environment is unlikely to happen unassisted. The environmental factors presented in the literature are predominantly associated
with facilitating engagement, collaboration and cooperation of the consumer. A summary of the factors that facilitate consumer participation in shared decision making processes at the individual level include: inclusion of the consumer in every point of contact with healthcare providers (McMillan 2001); inclusion of the consumer preferably prior to acute hospitalisation (Krupat et al 2000); continuity of healthcare provider (Page & Penn 2000); access to reliable information sources (England & Evans 1992; Elwyn 1999); access to decision related information and aids (Lorig et al 1999; Shepperd et al 1999; O’Connor et al 1999); time to reflect on personal values and preferences (Towle and Godolphin 1999); and, an environment conducive to discussion and negotiation of healthcare over sequential visits (Andrist 1997).

The aforementioned factors are indicative of a healthcare environment that is conducive to the provision of safe and high quality healthcare. These facilitating factors have been demonstrated to favourably influence both the consumers’ assessment of their health status, as well as independent clinical measures of health status. This is in comparison to consumers who were exposed to traditional healthcare environments, such as those that support the medical model of decision making (Kaplan, Greenfield, & Ware 1989b; O’Connor et al 1999).

**Integrating Participation into Healthcare Practices**

Although the factors mentioned above appear fairly easy to integrate into healthcare practices; nonetheless, shared decision making remains a contentious issue. Healthcare providers have reported struggling morally and ethically between balancing beneficence and patient autonomy. Woodward (1998) exemplifies this struggle in describing situational scenarios, such as when a provider perceives a consumer’s decision to be potentially harmful and self-injurious and where the consumer refuses the care that is advocated. Another example is where consumers may comply with interventions because they wish to please the provider, or conversely may perceive themselves to be bullied into compliance (Rankin 2001). Consumers may also elect, despite
encouragement, to adopt a more passive and dependent role in decision making (Redfern 1996).

A recent Australian cross sectional observational study, exploring adult consumers’ (n=212) preferences for autonomy in decision-making in the management of moderate to severe asthma by Adams et al (2001), identified that consumers preferred their healthcare providers to assume the major role in most decisions. However, the consumers did retain some control in decision making. The findings indicated that the most significant factor that influenced the consumer initiating autonomy in the management of their asthma was fear, concerns and attitudes. The consumers’ perception of the propensity of the healthcare provider wanting to involve them in decision making was influential on their preference for self management. Adams et al (2001) suggested that, due to the diversity of consumer preferences for autonomy across a wide range of variables, the most effective way of ascertaining an individual’s desire for involvement in decision making is to ask him/her. However, this approach does not yet appear to be current practice for healthcare providers.

An obvious finding from the literature review is that each individual had a different perception or interpretation of his/her own reality. The philosophy of consumer participation is about enabling individuals, and to enable is to be inclusive and offer choices. Consumer perception of inclusion in decision making is a significant aspect of this study, and one which will be explored further in this literature review.

Summary - Sharing the ‘Uncertainty’ - Information Sharing and Decision Making in Healthcare

The consumer/provider relationship is commonly centred on information sharing and decision making. These characteristics are as complex as they are simple. Elwyn (1999) aptly describes the partnership in decision making as sharing the uncertainty. Serendipitously the shared approach to decision making has had a destabilising effect on what was previously unchallenged; that is, the providers’ decision making autonomy. This has generated uncertainty; an uncertainty that health providers have not been trained or skilled to respond to.
Key findings from the literature include:

- It is not the approach that is taken to healthcare decision making that is relevant; instead, it is the concept of valuing both the expertise of the provider, and the experience of the consumer that is significant.

- Decision making is a rationally responsive process which is not conducive to standardisation or generalisation.

- Participation is a voluntary choice and the most effective way of ascertaining an individual’s desire for involvement in decision making is to ask him/her.

- Shared decision making and information sharing is influenced by environmental and service issues.

- Each individual has a different perception or interpretation of his/her own reality – this study intends to explore consumer’s perception of inclusion and decision making.

- Healthcare providers attach a considerable value to the responsibility of healthcare decision making, which they are unlikely to willingly give-up just because they are told to.

The literature suggests that healthcare as a social model, is a neophyte in actively addressing or attempting to influence the complexity of behaviours and attitudes linked to decision making. Based on the literature, which highlights numerous variables and layers of context, it is not difficult to understand why these aspects of the consumer/provider relationship have been left ignored, and thus continues to reflect the traditional medical model. This being the case, it is also an unwarranted expectation that consumers will know how to participate equally in healthcare decision making. It should also not be unexpected that consumers may be fearful, or just not want to participate, let alone self manage their healthcare.
Section Two Summary

The literature review thus far, provides an overview of consumer participation at the individual level of healthcare. The association between facilitating the individual’s participation in his/her healthcare and the propensity to influence the quality and safety of healthcare has been made by both National and International experts. Replicating the unanimous support for a participative healthcare model highlights the difficulties in determining the presence, impact and effectiveness of consumer participation using the scientific method of inquiry. The efficacy of a social science or triangulated approach to obtaining meaningful evidence has been argued, and compared to attempts to facilitate or measure behavioural change in healthcare providers.

Consumer participation at the individual level of healthcare has been broken down into the active components of decision making and information sharing. These components are then broadly categorised into a framework illustrating the characteristics of the paternalistic, shared decision making and informed choice approaches. The literature supports that it is not the approach that is taken to healthcare decision making that is relevant; it is the concept of valuing both the expertise of the provider and the consumer that is significant. The research also identifies that decision making is a rationally responsive process, which limits its capacity to be standardised or generalised.

The individual variables and context issues that potentially influence healthcare decision making have been outlined. Two strategies to manage the uncertainty of involving consumers stood out from the literature. Firstly, the need to remember that participation is voluntary, and to simply ask consumers the level of decision involvement they expect or want. Secondly, if clinical guidelines are mandatory, then do not involve consumers in decision making.

A recurrent theme relevant to this study is that there has been minimal consideration given to preparing or supporting the individuals directly involved in practicing consumer participation. In what has been described as a top-down endorsement of the consumer focussed model, health services
appear to have dismissed the significance of changing traditional behaviours and attitudes of healthcare providers. The literature suggests that healthcare providers, particularly doctors, associate their traditional role in decision making as a fundamental component of their self image and job satisfaction. In addition, providers have also integrated strategies into decision making that distance them from the consumer as a method to minimise stress associated with their role. Taking, or threatening to take, the principal responsibility for decision making away from the provider, without supporting them in exploring alternate stress management strategies and professional identity concepts, is unlikely to result in compliance or a sustainable change in behaviour. The literature has identified that preparation of the consumer also needs to be considered. In particular, providing opportunities for consumers to voice their perceptions of what they expect, want, or perhaps fear from healthcare decision making. Consequently, this study aims to explore the views held by both the consumers and providers on healthcare decision making and information sharing.

Participation in individual healthcare, information sharing and decision making will now be reviewed in the context of the maternity care setting and the condition of elective caesarean section (ECS).

Section Three: The Scenario

This section of the literature review links the previous context and philosophical principles of consumer participation, to this study’s specific focus. Firstly, consumer participation is reviewed within the context of the Australian maternity care setting, followed by a targeted review of participation in relation to elective caesarean section (ECS). Consumer participation in ECS at the individual level is then scrutinised within the context of the decision making and information sharing elements of the healthcare relationship.
Participation in the Maternity Care Setting

Maternity care is often favourably referred to as unique from other services within health. It is unique in that there is a perception that consumers frequently determine the details of their own health management. Quinlivan, Petersen and Nicholas (1999) make this assertion on the basis of a prospective study tracking the trajectory of decisions that women (n=633) made in relation to ECS at a Western Australian public hospital from 1995 to 1997. Based on medical record documentation, the study found that 170 (27%) ECSs were performed solely at the woman’s request. This was the leading indication for performing the operation. Of the 170 women requesting an ECS, 103 had a history of one previous caesarean section, but their current pregnancy was suitable for vaginal birth, 56 were a breech presentation and five had no medical history and requested an ECS on the grounds of personal choice. The authors argue that this finding is representative of women’s choice: to decide their method of contraception; to continue with a pregnancy or not; to deliver at home, in a birthing centre or in hospital; regarding the management of labour and delivery, including the type of analgesia; to have an episiotomy and whether to have a caesarean section or not (Quinlivan et al, 1999). This can be seen to be a rather a simplistic view, devoid of numerous variables; however, it is a widely accepted view that women have the option to choose in maternity care.

Maternity Service Reviews

Consumer advocacy and consumer choice can be traced to the Australian women’s movements of the early 20th century (Marsden 1996) and women today are still identified as the driving force in maternity care reforms. In 1991, a national working party was established to review current practice in childbirth services in Australia (NHMRC 1996). This review produced a revolutionary report that placed, side by side, the variances in clinical methods, interventions and outcomes of maternity care, with the consumer’s attitudes and concerns. As a result, ‘Options for Effective care in Childbirth’ (NHMRC 1996) was published. This report merged significant findings and
recommendations from data reported in three states, ‘Having a Baby in Victoria’ (1990), ‘Maternity Services in New South Wales; The Shearman report’ (1989) and ‘Review Obstetric, Neonatal and Gynaecological Services in Western Australia’ (1990), with the evidence for effective maternity care based on randomised clinical trials and the evaluation of clinical practice (Chalmers et al. 1989).

The NHMRC report (1996) detailed fifty-eight recommendations. Amongst these, it was recommended that maternity services should; feature time for consultation and discussion, improve communication and accept shared decision making between consumer and provider. The report argues that consumers’ knowledge of healthcare options and provision of appropriate information was a fundamental issue that had yet to be appropriately addressed. As a result, it continues to be the norm that women are making choices based on limited access to information, or choices that reflect the usual practice of their healthcare provider.

Three years later the Senate Community Affairs Reference Committee reviewed maternity services again, ‘Rocking the Cradle; A report into Childbirth Procedures’ (1999), with one of the purposes being to examine the dissemination and implementation of the NHMRC (1996) recommendations for effective care in childbirth. The Senate (1999) reported that in contrast to the NHMRC’s intention for decision making and information sharing as quality improvement mechanisms, these features were found to have been misinterpreted. Instead, interventions were introduced to monitor healthcare complaints and to avoid adverse events and/or possible litigation rather than promote a partnership approach. The Senate (1999) provided an example of how recommendations intended to enable the individual to participate in decision making, such as service produced information pamphlets and education sessions, were being used to control or create an image of choice within institutionally defined boundaries. The data reported to the Senate (1999) also demonstrated that variations within clinical practices between maternity services, between professional groups, within clinical settings, and within consumer populations, were consistently inconsistent.
Defining Quality in Maternity Care

In an attempt to link clinical data collection and outcomes with consumer measures of service quality and safety, the report (Senate 1999) also recommended the development and publication of clinical indicators that reflect the consumers’ perceptions of maternity practices. This recommendation was supported in the Consumer Focus Collaboration (CFC) summary report, ‘Review of Existing Models of Reporting to Consumers on Health Service Quality’ (2000d). The CFC stated that it was well documented and that any correlation between the consumer’s definition of quality and the quality indicators used by health care services would be dependent on the consumer being involved in developing the indicators.

The Senate (1999) acknowledged the operational difficulties in designing and implementing consumer oriented quality indicators for maternity care. Limited resources, ineffective dissemination mechanisms, lack of incentive, fragmented services and information asymmetry between consumers and healthcare providers were some of the major barriers that the Senate (1999) identified in Australian maternity services.

Summary - Participation in the Maternity Care Setting

The maternity care setting claims, and is recognised, for being a pioneer in the provision of consumer oriented healthcare; however, as outlined earlier in this literature review, the operational challenges that face acute public hospital settings are not dissimilar to the challenges faced by maternity care services. The 1999 Senate report into maternity services has dismissed the myth that women centred care exists beyond the policy level and revealed that maternity care quality measures are predominantly defined in terms that meet the needs of healthcare services, rather than those of the consumer.

It is an aim of this study to explore whether the organisation of maternity care is consumer oriented and whether the decision making aids produced and disseminated by the maternity services are designed to enable individuals to
participate in decision making and make informed choices related to their maternity care.

**Participation and Elective Caesarean Section Healthcare**

‘Rocking the Cradle; A report into Childbirth Procedures’ (1999) states that the surgical procedure, caesarean section, has aroused great interest and concern among members of the community and health professionals. In maternity care, a caesarean section is classified as *elective* if the decision to operate is made before the onset of labour, in contrast to an *emergency* caesarean section, where the decision to operate occurs after the onset of labour (NSW Public Health 2001).

Of greatest concern to the Senate (1999) is the gradual but persistent rise in the national elective caesarean section (ECS) rate to one of the highest in the world. The Senate report quotes the 1997-98 National Hospital Morbidity (Casemix) Database figures which indicate a national caesarean section rate of 21%. An unenviable comparison is presented, in that the Australian rate, for the first time exceeds the USA, a country that is renowned universally for an unjustifiably high caesarean section rate (1999).

**Variations in Elective Caesarean Section Practices**

*The Australian Institute of Health and Welfare* AIHW (2000) report that the surgical intervention of elective caesarean section (ECS) has variations in rates and practices that cannot be adequately explained. Such variations exist within and between: States and Territories; healthcare facilities; professionals; and, maternal demographics (Senate 1999).

A healthcare provider’s decision to perform an ECS has been explored from a number of viewpoints (Senate 1999). The AIHW (2000) argues that the deficit of current information on practitioner variations in ECS rates is due to a lack of empirical data to explore individual practitioner behaviours since the condition has been removed from the medical benefits schedule in the late 1980s. However, the Senate Committee (1999) reports anecdotal evidence to
support that the healthcare provider’s clinical practice decisions are influenced by: their professional background and philosophy; the institutional culture of the health service; peer pressure; and, the threat of litigation in the event of a less than optimal outcome following refusal to preform a requested caesarean section.

The Senate Committee (1999) also examined the current literature and collated anecdotal submissions across the nation, compiling a comprehensive list of factors that may contribute to the women’s decision for an ECS. Some of these factors include: the relative safety and widespread availability of the option; media influence; maternal age; number of pregnancies; technological culture; convenience; fear of pain and/or possible risks of vaginal birth; partner’s preference; private health insurance; education level; female obstetrician; and, career path.

In support of these factors, Paterson-Brown (1998) argues that if women were fully informed, expressed a logical reason and could demonstrate understanding of the implications, then their choices should be respected. Referring to the earlier discussion, in this literature review the level of participation in healthcare decision making is a difficult concept to validate or accurately predict; thus, determining whether a woman is fully informed is equally problematic. The Senate’s Committee (1999) findings further support being cautious in interpreting healthcare decisions stating that, ‘doctors would be unlikely to admit to, or document, performing operations where there is no medical reason and the fear of litigation exists’.

The least explored factor in the Senate report (1999), potentially influencing the variation in ECS practices, was the dynamics of the relationship between the consumer and healthcare provider. This healthcare relationship remains potentially one of the most influential and yet least understood factors. This finding is compatible with the emergent theme of this literature review, in that the perceptions, beliefs and attitudes of the individuals who form the healthcare partnership, have yet to be meaningfully explored. Consequently, this study aims to contribute to filling this gap in the healthcare literature.
Elective Caesarean Section Information Sharing and Decision Making

Paraphrasing an editorial published in the Medical Journal of Australia (de Costa 1999), ECS consumers have the enviable opportunity to participate actively in the decision making process, with ample time to discuss and debate the surgical procedure. This view will be explored using the handful of articles on consumer participation relevant to this study.

The Rhetoric of Consumer Choice

In 2000, Appleton, Targett, Rasmussen, Readman, Sale, Permezal and the Australian VBAC Study Group, published the findings of an Australian multicentre study on the rate of the surgical procedure Vaginal Birth after Caesarean Section (VBAC) over a five year period (1992-97). Although it was not the stated intention of the VBAC Study Group, their study exemplifies the complexity of defining the consumer/provider decision making relationship. Its focus is on the consumer group, women with a previous history of caesarean section, who’s birthing options included an ECS or attempted vaginal birth. The VBAC study’s methodology was a retrospective analysis of 21,452 medical records by clinician reviewers using a standardised summary form, plus individual case reviews. The VBAC Study Group noted that a limitation of using the ICD 9M medical record coding as the principle data source, was that emergency and elective caesarean sections were unable to be differentiated (Appleton et al 2000). This resulted in estimations and assumptions being made on the sample size and clinical outcomes.

In their analysis of clinician documentation in the case note sample, Appleton et al (2000) described the healthcare providers’ behaviours, as being generically uneasy about the VBAC procedure and a definitive site bias was noted where there was a special interest for the procedure (i.e. individual clinicians or sites that had an enthusiasm for the VBAC procedure were significantly more likely to have a higher VBAC rate in contrast to more cautious sites). The approach to decision making was described as being characteristic of informed choice, illustrated previously in Figure 2.1 (p.25)
where the woman is credited with making an autonomous decision after being provided with relevant information from her healthcare provider. The study however, did not validate the elements of the decision process that led to the assumption of informed choice. Indeed, in contradiction, the authors reported that in their expert opinion, the VBAC rate of a setting might be more aptly described as an indicator of a clinician’s attitude to VBAC, rather than the woman’s preference or clinical risk factors influencing the decision (Appleton et al 2000).

The VBAC Study Group’s findings, endorse the NHMRC (1996) and Senate (1999) concerns that women were vulnerable to being manipulated so that their choices reflected practice norms. Equally, Appleton’s (2000) findings challenge de Costa’s (2001) suggestion that a debate precedes the decision making process for an ECS. A debate is described in the Macquarie Dictionary (1985) as an ‘open discussion, deliberation, and a systematic process of disputing two opposing points of view’. Rather than debate, Appleton’s (2000) findings describe the information asymmetry that the Senate (1999) reports to be adversely impacting on the decision making process.

Involvement and Satisfaction of Women with Information Sharing and Decision Making

The dynamics of the decision making and information sharing that precedes caesarean section is described in the Senate (1999) report as an area that little is known about. The evidence most often referred to by the Senate in chapter five of their report, Interventions in Childbirth - Caesarean Section, was that from the Australian study by Turnbull, Wilkinson, Yaser, Carty, Svigos and Robinson (1999a). This study examined 278 women’s involvement in caesarean section decision making and satisfaction with maternity care, at a tertiary referral hospital in Adelaide between July and December 1996. Their study intended to address the criticism of previous studies that had explored the perspective of women and healthcare decision making. The limitations of previous studies included; small homogenous samples, not representative of the population, and findings which could not be generalised to the wider Australian population (Turnbull et al 1999a).
Turnbull’s (1999a) study design involved a consecutive sample of eligible women (18 years and over, comprehended English and well enough to participate) who underwent a caesarean section in one public hospital. The study’s questionnaire, designed by the authors, included forced choice responses, open ended and demographic questions. The questions focussed on women’s involvement in the decision to have a caesarean section, reasons for the decision and satisfaction with the decision. The women were approached during their hospital stay, written consent was obtained and the questionnaire was sent to their home seven weeks after the birth. The time delay was proposed to minimise bias related to the halo effect and socially desirable responses that have been associated with questionnaires completed during the hospital stay or soon after discharge (Turnbull et al 1999a).

The questionnaire response rate was a favourable 76.4% of the sample. For the purpose of this study, the responses of women who experienced an ECS were specifically extracted. Eighty-six survey responses were from women who had undergone an ECS. Seventy (81.4%) of these women reported involvement in their ECS decision compared with 53.2% of the emergency caesarean section sample. This finding could be seen as supportive of de Costa’s (2001) generalisation that women having an ECS were likely to have input into the decision making process. However, even more important, is that sixteen women who had an ECS, perceived that they were not involved in the decision to have what is essentially a voluntary surgical procedure, an intervention that requires informed consent. Obtainment of informed consent is a legal procedure that is preceded by debate and the attributes of informed consent are described in the Professional Ethics for Health as including information exchange and fostering autonomous decision making (Berglund 1998).

A limitation of Turnbull’s (1999a) study design was that the responses to the open ended question, ‘what led you to make the decision to have a caesarean section?’ were not able to be separated into elective or emergency responses, impairing interpretation. However, the forced choice responses in this question bank were separated. The forced choice question listed twelve factors
(based on previous studies), and asked the women to indicate whether each factor influenced their reason for deciding to have an ECS. The three most frequent responses for deciding to have an ECS were: 1. information from doctor (75.7%); 2. consideration about recovery (60.0%); and 3. partner attitude in general (44.3%). By comparing the ECS responses to the emergency caesarean section responses, the ECS sample were twice as likely to have been influenced by an ability to plan, to be concerned about pain and have had a previous ‘awful’ pregnancy labour. Interestingly, the ECS sample was nearly four times as likely to report that the views of their family and friends were influential on their decision. Considering the views of family and friends in preference to healthcare providers for decision making information is a trend that is supported by the Consumer Focus Collaboration report (2001).

Factors that were noted by Turnbull et al (1999a) to influence preference for a caesarean section across the total sample included the demographic categories of intermediate education category and private obstetric care. The Senate report (1999) reiterated the marked difference between an increased caesarean section rates for women with private obstetric care compared to those who receive public maternity care.

Another limitation of Turnbull et al’s (1999a) study design was that the demographic data and interpretation of satisfaction with decision making and information sharing were aggregated and analysed as a collective sample. This was despite Turnbull et al (1999a) introducing their study with the argument that the perceptions and needs of women who elect an ECS, were different to those of their emergency caesarean section counterparts. The absence of individual analysis of the study data, in particular consumer satisfaction, is disappointing for informing my study.

In response to the multiplicity of factors associated with women’s involvement in caesarean section decision making and their satisfaction with maternity care, Turnbull et al’s main recommendation was to undertake a randomised trial of a broad based information package for women and their family/friend network.
In the context of Turnbull et al’s findings, this recommendation stood out as a contradiction. A randomised control trial implies a controlled environment, an homogenous sample and outcomes that may be generalisable, whereas Turnbull et al’s study had just painstakingly identified the variances that influenced the samples responses. Furthermore, a ‘Readers Response’ to Turnbull et al’s (1999a) publication suggested to the authors that in reading the conclusions, it implied that it was the women who were the sole blame for the decision to opt for a caesarean section (Chung 1999). In response, Turnbull & Wilkinson (1999b) strongly denied that this was their intention, yet their recommended intervention does actually imply to the reader that it is the women who needs educating and updating, not the healthcare system or the healthcare providers.

Turnbull et al’s (1999a) study design, retrospective survey of women’s involvement in decision making and information sharing is similar to the methodology of this study. Turnbull et al’s data analysis highlighted that aggregating responses may distract from the significance of individual responses. It is hoped that this study’s method may provide a more balanced interpretation of the factors that influence decision making by exploring the views and behaviours of healthcare providers, environmental issues and of course the consumer.

Women’s Preferences for Elective Caesarean Section

Gamble and Creedy (2001) undertook a study that was aimed to fill a perceived gap in Australian research on women’s birth preferences and the reasons and factors associated with their preferences. The Brisbane based study recruited eligible women (between 36 – 40 weeks gestation, 18 years of age or over, who comprehended English) from the antenatal clinic of a public tertiary referral hospital and the consulting rooms of six obstetricians over a four month period (Gamble & Creedy 2001). A four-part questionnaire was designed and piloted for the study. The questionnaire was categorised into demographics, details of previous birth(s), current pregnancy and a standardised anxiety measure.
The response rate of 97% reflected the data collection procedure, where women were approached while waiting for their antenatal appointment. Consent was obtained and the questionnaire completed with the independent researcher available as a resource if required (Gamble & Creedy 2001). For the purpose of this study, Gamble & Creedy’s findings were critiqued for reference to decision making and information sharing for elective caesarean section women, and the findings will be compared with those from Turnbull et al’s (1999a).

Twenty women, 6.4% of the sample, reported that they would like a caesarean section (4 nullipara and 16 multipara). All of the multiparous women (n=16) had experienced a previously complicated birth, three of the nulliparous women (n=4) were expecting a breech and one nullipara, in the absence of obstetric risk factors, reported she preferred a caesarean (Gamble & Creedy 2001).

The data analysis included exploring the level of preparation and knowledge of the caesarean preferred sub-sample (n=20). The level of preparation was positively influenced by the women, already being booked for the procedure. This compares to Turnbull et al’s ECS sample, where the ability to plan was an influential factor (Turnbull et al 1999a). The level of knowledge of the caesarean preferred sub-sample (n=20) was ascertained by their responses to recording a self-assessment of an advantage and a risk of the procedure for themselves, and their baby. The majority of the women recalled an advantage (advantage to mother 90% (n=18), advantage to baby 95% (n=19); however, only a small proportion recalled a risk (risk to mother 40% (n=8), risk to baby 5% (n=1). The authors commented that the intensity of the risks cited by the sample were minor compared to the ‘life saving’ advantages. Interestingly, the authors identified that the only woman who recalled a risk to her baby associated with the procedure, was the nullipara woman with no obstetric risk factors (Gamble & Creedy 2001).

The demographic variables of age, marital status, education level, occupation, ethnicity or type of healthcare (public/private) were not significantly
associated with the stated birthing preferences of the sample. However a relationship was identified between the State anxiety scores, whereby the caesarean preferred sub-sample was found to have significantly higher anxiety scores than women preferring a vaginal birth. Similar to Turnbull et al’s (1999a) findings, women from the sample who described their birth experiences as awful, unpleasant, or frightening were more likely to prefer caesarean section as their birthing option. Another similarity to Turnbull et al’s (1999) findings, was that the caesarean preferred sub-sample’s (n=20) response to reasons that influenced preferences, included their doctors recommendations, 25% (n=5) and concerns for pain, 20% (n=4). However, in contrast to Turnbull et al’s (1999) findings, the most influential reason stated from this sample for preferring a caesarean section was for the safety of the baby, 40% (n=8)(Gamble & Creedy 2001).

A conclusion that can be drawn from the literature is that birth preferences are not simply a choice between two equally acceptable options. However, it was interesting to note that 25% of Gamble & Creedy’s (2001) caesarean preferred sample (n=20) were significantly influenced by the recommendations of their doctor, compared to none (0%) of the preferred no analgesic vaginal birth women (n=170), and two (1.6%) of the preferred vaginal birth using analgesics women (n=120). It was suggested that healthcare providers, downplaying the negative aspects or risks of procedures during consultation, might have influenced the women’s interpretation of risks. Although the women’s sources of information were not sought in this study, the authors concluded that a lack of access or inadequate information might be an issue during the process of obtaining informed consent. Considerations towards facilitating sensitive discussion and mechanisms for tracking women who had previous traumatic or negative birth experiences were recommendations of the study (Gamble & Creedy 2001).

Women’s apparently poor self assessment and knowledge base of potential risks when stating their preference for a caesarean section (Gamble & Creedy 2001) should not be judged in isolation, because a similar preference for a caesarean section has also been suggested as an option for those considered
highly informed. Al-Mufti, McCarthy and Fisk (1996) surveyed a sample of London obstetricians who responded to hypothetical pregnancy situations. The survey found that 31% of female obstetricians and 8% of male obstetricians responded that for an uncomplicated singleton cephalic presentation at term, they would choose elective caesarean section for themselves or their partner. The obstetricians’ self assessment of risk mirrors Gamble & Creedy’s (2001) caesarean preferred sub-samples’ responses, in that they tended to cite the potential maternal physical damage from a vaginal birth or recovery from a surgical birth as risks, rather than clinical or safety risks.

The similarities between women’s responses within a prospective study (Gamble and Creedy 2001) and a retrospective study (Turnbull et al 1999a) in relation to ECS are encouraging for this study, because the methodology is a retrospective consumer survey. The studies reviewed have identified central themes such as; access to, sharing of and interpretation of information as being influential on the decisions women make. The significance of these themes is summarised below

**Summary- Elective Caesarean Section Information Sharing and Decision Making**

The Australian literature reviewed for the purpose of this study has focussed on exploring the woman’s involvement, motivation and satisfaction with decision making for a caesarean section (Appleton et al 2000, Turnbull et al 1999a, Gamble and Creedy 2001). For the purpose of understanding healthcare decision making, the studies’ outcomes reflect the methods used in that they failed to effectively capture the dynamic elements of decision making; rather, they focussed on exploring and analysing just one component, primarily the woman. In other words, the methods used have marginalised the potential to improve future decision making in relation to ECS.

A focus of the Australian literature has been on improving the woman’s decision making capacity, whilst the provider’s contribution, identified in each study as being one of the most influential reasons for a caesarean, remains incontestable. This is considered a limitation of study design; however, it
could also be a result of the exploratory nature of the research and the limited access to comparable research. Alternatively, it is viewed as socially acceptable to question the knowledge and ability of the woman, rather than to critically review the shortcomings of the provider or health system.

Commonality in participant demographics is a feature of the literature, with the women electing or preferring a caesarean section likely to be: multiparous; have had a previous awful birth experience; be concerned about pain; prefer to plan events; and, be influenced by doctors’ suggestions or information from family and friends. The studies samples were limited to respondents who were over 18 years of age and comprehended English. The portion of the sample that was specifically related to ECS was limited and the data was frequently aggregated; consequently, this hindered exploring the responses and experiences of ECS participants comprehensively. Refraining from aggregating individual responses in future studies may make the data in relation to the dynamic process of decision making more meaningful.

Facilitating Participative Relationships within Maternity Care

In ECS decision making, an interesting paradox has emerged from the literature. Women are both encouraged and criticised for expressing their expectations and interpretation of the ECS risk/benefit ratio. This contradiction does not suggest that partnership in decision making for ECS is supported, or in fact that generic facilitation of partnership in health related decision making would be supported in the acute public hospital setting.

Participative Environment

Greco and Eisenberg (1994) reported to the health professional community that the efficacy of change interventions in healthcare would be impacted by the variable circumstances of the clinical area. This advice has been further expanded by Andrist's (1997) suggestion that engaging in a decision making partnership implies the existence of trust, knowing and sharing. These findings supported Berglund's (1998) opinion that a setting which has a stable
environment, that is conducive to negotiation and information disclosure, will be an environment that activates participation.

From a maternity care scenario, Page & Penn (2000) have argued that the current fragmented public maternity care models adversely influence the probability of healthcare provider continuity during pregnancy care, and therefore marginalise participation. Environmental conditions in hospital settings were generalised by Page & Penn (2000), who described them as not conducive to the discussion of complex or personal issues. The Senate report (1999) also voiced concerns that the shared maternity care model in Australia, involving small teams of general practitioner obstetricians and midwives, is vulnerable to fragmenting the provision of healthcare because there is an absence of infrastructure to facilitate continuity, between healthcare providers or within healthcare organisations.

An environment such as this has a number of implications for participation. One is the reported variation of individual clinical practices and views held by health providers (Senate 1999), another is the limited capacity of the provider and consumer to establish a relationship and trust over subsequent visits (McMillan 2001).

Participative Relationships

The suggestion that healthcare providers and women might benefit by allowing time to reflect on previous birth experiences, critiquing them together to form a common understanding, was an outcome of VandeVusse's (1999) qualitative study of 33 women's birth stories. Turnbull et al (1999a) recommended providing women with more information, particularly those women who had experienced awful previous birth experiences and had concerns about pain. This recommendation implies that reflection and more time to communicate is beneficial; however, the Turnbull study (1999a) explored information sharing on the level of being given or needing information, rather than critiquing or reflecting on information; thus failing to explore information sharing as a relationship or as an environment that needed supporting.
Brown (1996, cited in VandeVusse 1999) found that consumer/provider informational politics existed in the clinical setting, in that women preferred an open flow of communication. This flow could be effectively facilitated or obstructed by the healthcare provider depending on the dynamics of the relationship. The partnership was stated to be the most vulnerable in the introductory or formative stages, when the consumer is first exposed to the behavioural norms of the provider and the institution.

The Providers Influence on the Maternity Care Relationship

In the literature reviewed, the healthcare provider’s contribution to the decision making relationship tends to be discussed anecdotally. Appleton et al (2000) were clear in their suggestion that the decision to elect a caesarean section might be more aptly described as an indicator of the attitude of the provider or service, rather than the woman’s preference. This opinion is supportive of the Senate’s (1999) concern about discounting provider bias as a cause for the rising rate of caesarean section. Al-Mufti et al (1996) identified in their analysis of obstetricians’ preference for ECS that more than a third of the sample, in the absence of complications and for relatively minor preventative risk indicators, would personally elect for a caesarean section for themselves or their partner.

The number of Australian studies is limited. In a study designed to explore whether Brazilian women were really choosing to deliver by caesarean section, Hopkins (2000) examined the decision making dynamics and the healthcare provider’s contribution to decisions. The study was set in an environment described as having an epidemic of caesarean sections, with 1997 data recording that 37% of Brazilian births end in a caesarean section, more than twice the WHO’s recommendation of 15%. The study aimed to investigate the phenomenon that was promoted by the medical providers, that women demanding a caesarean birth were the cause of such a high rate.

In contrast to the methods discussed previously in this review, (i.e. doctors’ views and women’s motives for caesarean explored independently), Hopkins’
(2000) study sought to explore the dynamics of the decision making relationship, in particular the power differences between doctors and women. Hopkins collected data from a postpartum survey, participant observation in hospital, interviews and analysis of conversations between doctors and women during labour and delivery (2000).

The findings suggested that healthcare providers have established mechanisms to manipulate the decision making relationship, through their technical expertise and authority, in order to convince the woman that she has chosen a caesarean section. Hopkins (2000) suggested that the women's vulnerabilities in relation to fears of pain and previous birth experiences were overplayed to the advantage of the medical provider, with the concept of caesarean section being suggested and overestimated in its safety. The two significant motivating factors for the medical provider were convenience and more control over time management. Although the study was set in Brazil, a number of parallels can be drawn to the vulnerabilities of the Australian population (Turnbull et al 1999a, Gamble and Creedy 2001) and women making choices that reflect medical and organisational cultures (NHMRC 1996, Senate 1999, Appleton et al 2000).

Section Three Summary

The image of a woman centred maternity care model is not supported by the literature and reports reviewed. Even though service provision and policies have been restructured under the guise of creating and facilitating options and choices for women, the literature suggests that clinical practice and information sources continue to reflect institutional norms and surveillance systems rather than consumer preference or participation. Variations in clinical practices are more likely associated with the preferences of the healthcare provider or organisation, rather than from the woman’s contribution to the decision.

The reliability of the literature related to consumer participation in designing individual maternity care for ECS is limited. The methods used, hindered
attempts to accurately reflect or measure the dynamic nature of the decision making relationship. Studies tend to focus on addressing the inadequacies of the women’s participation collectively; neglecting the interaction with the provider and the organisation. This has an impact on the ability to predict associations or relationships about the individual variables of the healthcare relationship, in particular the decision making and information sharing components.

The generic environmental, professional and social factors that create a setting conducive to activating participation in decision making are alluded to in the literature (VandeVusse 1999; McMillan 2001; Page & Penn 2000). The propensity for power imbalances, manipulation and information politics within the maternity care relationship are also suggested (Turnbull et al 1999a; Hopkins 2000; Gamble & Creedy 2001; NHMRC 1996; Senate 1999). However, the literature has yet to capture and correlate the salient features of these elements; giving integrity to the complexity of healthcare decision making.

In relation to this study, it is considered that the multi-method approach will go someway to minimising the limitations of the current literature. By capturing the consumers’ perceptions of involvement in decision making, the views and behaviours of healthcare providers towards including consumers in decision making and an audit of the participative attributes of the environment, I have the opportunity to explore the consumer’s participation in decision making at the individual level of healthcare. Reviewing individual responses independently is time consuming; but the inability to generalise and the loss of meaning found to be associated with aggregated data, suggests it may be time well spent.

This chapter has so far reviewed the published literature in relation to consumer participation in individual care within the maternity care setting, and in particular decision making and information sharing related to ECS. This will now be followed by a discussion of current methods of monitoring or measuring outcomes of consumer participation and then the role of the medical record in the hospital setting.
Section Four: The Outcome

The previous sections describe the organisational and social dimensions of consumer participation, as well as the preparatory components for activating a participative healthcare relationship on an individual level that have relevance in both generic and maternity care settings. This section will review the methods of measuring these qualities, commonly expressed in healthcare as outcomes.

An outcome, as a measure of the qualities of the healthcare experience, is an evolving concept. In the traditional medical healthcare model, an outcome is the result of the provision of a service or performing a task on a dependent patient. The consumer in this patient role is not a participator, but an object of care, for which a physical outcome favourable to the provider is the goal (Bishop 1994). In the consumer oriented healthcare model, the patient is a participant, contributing to the biological, psychological, cultural or social outcomes of healthcare (Neale 2001).

The literature shows the consumer/provider relationship to be multidimensional, and therefore the potential health outcomes are also multidimensional. Defining the variables that reliably measure the dynamics of the individual and organisational relationships of consumer participation has challenged researchers for the past three decades. In essence, this section defines the measurable outcomes of consumer participation in healthcare on an organisational level and then an individual level, before finally reviewing the methods employed to measure outcomes.

Measuring Organisational Participation Outcomes

In 1973, Ruth Thomson, commenting on consumer participation and the USA national legislation, noted that the priorities of implementation varied between the Federal government and community level. At best, there was only a crude or vague correlation as to the effectiveness and therefore relevance of consumer participation in healthcare planning. It is interesting to note in
Australia that as recently as 2002, similar observations continue to be published.

Pioneering Organisational Participation Outcome Measures

Metsch and Veney (1973), two USA medical academics, in searching for consumer participation outcome data, explored the development of an alternate methodology to the then popular case study approach. In light of the literature reviewed, the methodology developed by Metsch and Veney (1973) remains unique, due to its rigorous encompassing approach. The method was designed to examine the progress of healthcare organisations in the implementation and adoption of consumer participation practices as a component of planning and management of healthcare services within target organisations. The methods used included: mailed questionnaires to board members; structured observations of board meetings; interviews with board members; and, a content analysis of the consumer advisory board minutes. The authors defined content analysis as:


..a technique for the systematic description of the manifest content of communication that replaces direct observations of formal communications that take place as a by product of a specific type of behaviour (Metsch and Veney 1973; p 369).

The study’s outcome measures included: the degree of consumer/provider interaction; the level of consumer input to decision making in the form of recommendations and requests; and, the extent of administrative responses or actions taken in relation to consumer input. Outcome scores were developed and weighted. The direction/control and interaction/integration of the observations recorded in the meetings minutes were measured. Metsch and Veney’s (1973) efforts were designed to provide an empirical measure, facilitating a clearer understanding of the phenomenon of consumer participation. Combining this with an assessment of the level of activity of participation within an organisation, the authors projected that a baseline of
consumer participation could be generated and linked into quality improvement strategies that measure change over a specified time period.

The authors found consumer board members were significantly less influential in agency decision making than provider board members and this difference existed even though no difference existed in their levels of participation (Metsch & Veney 1973). The reasons for this lack of influence were not specifically examined, although the authors identify some possible reasons, including ambivalence of staff attitudes towards consumer participation, lack of resources to support participation and a lack of a constituency for consumers to draw on for support.

Metsch and Veney’s (1973) methods were criticised at the time for their cost, both in time and resources, and the technical skills required to undertake participant observation, extensive interviews and questionnaires. The descriptive and subjective interpretative findings generated from the methods, were also criticised for apparently lacking the scientific rigour that health preferred; therefore, limiting replication and comparison of results. Interestingly, despite the reported limitations (which continue to overshadow contemporary consumer participation research) Metsch and Veney’s (1973) findings are congruous with the recent participation literature reviewed here.

Australian Organisational Participation Outcome Framework

Hilda Bastian (1996), an Australian health consumer advocate, was seeking ways of measuring the outcomes of the diverse consumer participation models being implemented in Australian healthcare organisations. Bastian argues that Dwyer’s (1989, cited in Bastian 1996) rationales for consumer participation remain relevant. These rationales fell into three broad outcomes:

- To improve services and decisions;
- To gain legitimacy and/or community compliance; or
- To bring about social change with the redistribution of power or resources

(Dwyer 1989 cited in Bastian 1996 p 486)
In her discussion on the literature related to fostering consumer involvement in clinical practice guidelines, Bastian (1996) is of the opinion that there is a growing acknowledgement of the need to actively involve consumers; however, she claims that the reality often falls short of the rhetoric. As a result of the range of interpretations and intentions of consumer participation in Australian healthcare, Bastian designed a framework (Figure 2.2) that draws from the Ladder of Participation (CFC 2000a; CFC 2000b; Arnstein 1969 cited in Bastian 1996) and the work of the World Health Forum (Bichmann et al 1989 cited in Bastian 1996). This framework is based on the concept that measuring the organisational level of consumer participation activity may be the most appropriate method of measuring the impact on health outcomes.

Figure 2.2 Levels of Consumer Participation

<table>
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<th>Level of Participation Activity</th>
<th>Health Outcome Measure</th>
<th>Description</th>
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| Wide Participation              | Improved               | Consumer representatives representing consumers’ views  
Consumer representatives representing consumers’ views  
Consumers widely consulted and participating |
| Open Involvement                | Improved               | Consumer representative(s) representing consumers’ views  
Consumers possibly consulted |
| Restricted Scope                | Marginal               | Experts advocating their perception of consumers’ views  
Possible token ‘consultation’ with consumers |
| Manipulation                    | Minimal                | Consumers ‘educated’ |
| None                            | Negative               | Consumers perspectives and concerns not specifically addressed |

Consumer activity that falls in the three lower levels of Bastian’s framework described the consumer as a passive participant, merely a source or recipient of information, which marginally influences health outcomes. The upper two levels describe participation processes that reflect partnership and a propensity for improved consumer health outcomes. Bastian’s association between increased levels of activity of participation, in the form of partnership at the organisation level of healthcare and improved health outcome measures, is supported by Kaplan, Greenfield and Ware’s (1989a) critical review of healthcare consumer/provider communication and health outcomes at the individual level.

Kaplan et al (1989a) analysed data from three separately conducted randomised trials and a fourth non-equivalent controlled trial. The clinical trial was conducted across four chronically ill practice settings, the sample included healthcare consumers diagnosed with ulcer disease (n= 45); hypertension (n= 105); diabetes (n= 59) and breast cancer (n= 43). The aim was to assess the effects of consumer/provider interactions on the outcomes of chronic disease. The intervention was designed to improve communication at the individual level and included improving the consumer’s capacity to participate in their healthcare (i.e. access to their medical record; a disease management algorithm that interprets their healthcare; and, coaching in behavioural strategies intended to increase participation). The intervention was administered by a research assistant just prior to planned consumer/provider interactions. The aim of the intervention was to change the provider’s behaviour by training the consumer to take a more active role in the healthcare interactions. The control group of consumers did not receive the intervention. They were provided with the standardised information for their illness; they were not provided with access to their medical record nor coached or encouraged to ask questions.

Kaplan et al’s (1989a) data collection methods included gaining a baseline measure of each participant in the study by audio taping the consumer/provider interactions that occurred during a regular healthcare visit. Other baseline data included physiological measures, and a self-report
questionnaire that explored participants’ perception of their health status, their preference for involvement in medical decision making and their satisfaction with care. The method of randomisation of each sample is not clearly detailed. The healthcare providers interacted with consumers from both groups, but were blinded to the control or intervention status of the individual consumer. The regular scheduled healthcare visits of each participant were then audio-taped. Kaplan et al (1989a) did not clearly detail the frequency or over what time period the intervention was administered. Post intervention data was collected 8-12 weeks after the last intervention session. The post intervention data included collecting physiological measures and re-administration of the self-report questionnaire.

Kaplan et al’s (1989a) findings indicate that a causal link, rather than an associational relationship, exists between the increased participation activity in the consumer/provider interactions of the intervention group and better health outcomes. Improved health status was demonstrated across the outcome measures, including physiological (blood pressure or blood sugar control), behavioural (functional status or capacity) and/or subjective (self report health status) measures (Kaplan et al 1989a). In closing, the authors lament the lack of meaningful understanding of the specific yet variable behaviours that influence healthcare participation at the individual level and assert the value of studying these issues further. This challenge does not appear to have been taken up as a priority area in contemporary healthcare research.

In essence, Bastian’s (1996) levels of consumer participation framework, although not empirically tested in their own right, are the summation of previous organisational research findings. Bastian’s link between increasing levels of participation activity and improved health outcomes supports Kaplan’s (1989a) findings. Another issue emerging from this literature review is that similar to the maternity care consumer literature, interventions and behaviour change strategies tend to be directed solely at the consumer aspect of the partnership. It is the aim of this study to interpret the environmental data in the context of Bastian’s (1996) framework, and to explore the relevance of the framework’s participation descriptors at the individual level.
of healthcare. In the data triangulation I aim to understand the dynamics of the healthcare relationship by acknowledging the provider, consumer and the environment as influential factors.

**Individual Participation Outcomes**

Consumer Satisfaction

By far the most popular method of gauging an individual consumer’s healthcare experience is through the measurement of *consumer satisfaction*. It is often quoted that consumer satisfaction with healthcare is a reflection of the effectiveness, efficiency and quality of the healthcare experience (Cleary et al 1989). With the emphasis for healthcare organisations on quality and outcome measurements (Donabedian 1988), it is surprising that consumers’ perception of their care and service beyond satisfaction, has not come under more scrutiny.

*Consumer satisfaction* measures are not unique to healthcare participation literature, and have been widely used in service industries, such as the marketing, retailing and the strategic business sector. However, in contrast to healthcare literature, retailing and business research have demonstrated a highly systematic and focussed approach to the investigation of consumer satisfaction. It has been speculated that differences in this clarity of focus can be accounted for by the business sector having a vested interest in identifying and addressing variables that mediate consumer satisfaction (O’Neal 1999). These same interests are not overtly recognisable in healthcare research. Healthcare providers have traditionally been more responsive to the technical aspects of providing care, and place a higher value on error-free technical care, than the consumer’s satisfaction with healthcare (Wilson et al 1996).

In healthcare, Bastian (1994) describes the mechanisms of monitoring and evaluating consumer participation as being only conditionally accepted as a component of service planning, and is more likely to be considered an optional or *add-on* feature. In reviewing the steps for developing and
conducting a patient satisfaction survey, Davis & Hobbs's (1989) literature review identified that satisfaction surveys tend to be loosely designed within a quality assurance framework. However, the descriptive evaluative feedback that results from these surveys is often lacking meaning due to the tendency to attract socially desirable responses from the patient (Davis & Hobbs 1989). An operational definition of patient satisfaction proposed by Davis & Hobbs (1989) is divided into three dimensions: access to care; care received (the human, clinical and outcome aspects); and, care environment. Applying these dimensions, Davis & Hobbs (1989) designed and implemented a patient satisfaction survey to 150 patients on discharge from a British Columbian rehabilitation service over a four month period. The aim was to feed the survey data back to the management, staff and hospital board and to develop action plans that addressed patient identified deficiencies as well as acknowledging areas of strength. One third of the satisfaction surveys were returned completed (n=50) and these surveys were predominantly positive; however, this trend was discussed as more likely to be an indicator of an ineffective distribution strategy rather than a measure of healthcare quality. The authors suggested that the sample may have been skewed because the providers were more likely to distribute and remind patients to complete the survey when they liked the patient or when their treatment had been particularly successful. During the study, the providers had to be reminded frequently to instruct the patient to collect a survey and the 150 surveys that were distributed represented only 10% of the patient population serviced by the providers. These findings are not unique to the Davis & Hobbs study. In reviewing the literature it was identified that satisfaction surveys are likely to be structured for the purposes of the organisation, and focussed on directing the consumer to respond to questions related to aspects and outcomes of care that were of interest to the provider, rather than to provide a patient’s description of the care received (Cleary et al 1989; Draper & Hill 1995).

Maternity Care Consumer Outcome - Satisfaction

Within a maternity care setting, satisfaction, as a self assessment outcome measure, was explained by Green (1999) as not just being about the consumer
having a positive experience, but about a positive evaluation of that experience. In the literature, maternity care consumer satisfaction is frequently measured by responses to a five-point scale ranging from strongly agreed to strongly disagree. Using this scale, a positive outcome measure or satisfaction is interpreted by the response of strongly agreed (Brown & Lumley 1994; Turnbull et al 1999a).

This literature review has identified that efforts to measure satisfaction with the decision to have an ECS tends to be restricted by the sampling techniques and methods used. For example, the data tends to be aggregated (Turnbull et al 1999a, Gamble & Creedy 2001) and where the ECS samples are identified, they are described as having unique information needs and decision influences when compared to the needs and influences of women having an emergency caesarean section (Brown & Lumley 1997; Turnbull et al 1999a). The studies’ methods mean that the aggregated data cannot be considered representative of what the individual consumer perceived of their healthcare experience or be interpreted as individual health outcome measures.

Satisfaction as a Valid Consumer Outcome Measure

The Consumer Focus Collaboration’s (CFC 2000b) review of the healthcare literature on consumer participation, feedback and diversity, identified that the participation literature tended to criticise the scientific flaws of their research, whilst also asking the reader to accept that the satisfaction measures presented were valid. Professor Cleary’s editorial in the British Medical Journal, asserts that, although numerous consumer satisfaction surveys have been completed, they have not had the expected impact on healthcare quality because they lacked the conceptual or methodological rigour that underpins an effective satisfaction survey process (Cleary 1999). In Cleary’s (1999) opinion, the pursuit of consumer satisfaction is unjustified in the terms of healthcare quality, and alternative methods, such as asking the consumer objective questions about aspects of care considered relevant to both the provider and the consumer, where the process can be validated and deemed reliable, are preferred.
Paul O’Neal (1999) also reviewed the literature associated with measuring consumer satisfaction. Like Cleary (1999) he was critical that the evaluation of human services, such as health, continue to endorse measures that are not validated, and also continue to report these measures as a proxy scale for service effectiveness or efficiency. Cummins & Baxter (1994, cited in O’Neal 1999) were quoted as claiming that to rely on either objective or subjective variables, when defining outcomes measures, are limiting the validity of the results. It is purported that by using objective measures alone, it is likely to reduce the personal value of healthcare in the results. By comparison, using subjective measures alone, the findings are unlikely to be validated or provide any real insight into service improvement.

Another criticism of measuring patient satisfaction is that patients might be satisfied with less than optimal healthcare or outcomes (Kaplan et al 1989a). Based on their literature review findings, the CFC (2000b) supports this suggestion and proposes that a patient dissatisfaction measure may be a more reliable outcome indicator. This argument questions the reliability of satisfaction data, whilst also questioning the science behind such data. Donald Berwick (1996) suggests that looking for the science behind such data, making the simple complicated, is likely to be an impediment to learning from the perceptions or reflections of the healthcare consumer.

This review of the literature highlights that consumer satisfaction is a subjective, unreliable measure that lacks scientific credibility. In acknowledging these limitations and also the potential for learning associated with the measure, this study will explore the consumer’s healthcare experience as multifaceted, measuring satisfaction as just one component that should be examined in tandem with other outcome indicators.

Dissatisfaction as a Consumer Outcome Measure

Based on the literature reviewed, the exploration of consumer dissatisfaction as a strategy for understanding healthcare outcomes is warranted. The study by Cleary, Keroy, Karapanos and McMullen (1989), was set in the quality
department of a British Columbian University Hospital. It is an example of how to gain an understanding of the consumers’ assessments of satisfaction with hospital care via a feedback survey, by comparing the survey ratings with the consumer’s healthcare record. A total of 598 anonymous surveys were completed by medical, surgical and obstetric healthcare consumers approximately three weeks after discharge. The retrospective survey included open and closed questions. The consumers (n=12) who responded that they would not recommend the hospital to others, were targeted. Comparison of the consumer survey rating and their healthcare record identified that primarily, dissatisfied consumers were those who were subjected to unpredictable and yet avoidable circumstances. The quality assessors identified, that documented in several of the healthcare records, were situations where the processes of healthcare, not its technical quality, were inadequate or inappropriate. It was suggested by the authors that reviewing consumer feedback, with providers and service managers within a risk management framework, was a useful way of highlighting the specific healthcare outcomes that can be improved through initiating interventions directed at facilitating consumer participation as well as improving the technical quality of healthcare (Cleary et al 1989). Consequently, reviewing the healthcare (or medical) records of consumers who express dissatisfaction with their inclusion in healthcare decision making and/or information sharing is a relevant inclusion for the methodology of this study.

Combined Satisfaction / Complaints as a Consumer Outcome Measures

A combination of outcome measures were also used by Wilson et al (1996) in their Australian study that explored the relationship between consumer satisfaction, complaints and technical quality of care. Satisfaction was measured by a questionnaire that was administered face to face whilst in hospital, and then repeated by telephone approximately six weeks after discharge. Technical assessment of care was measured using an outcome based medical record review program that was designed to detect and code actual or potential lapses in healthcare quality (Wilson et al 1995). Complaints were identified through formal mechanisms, the questionnaire process and the
medical record review. The participants were selected from Cardiac Surgery, Obstetrics and Oncology consumers. The total participant rate was 257/298 (68%).

With regard to the obstetric consumer sample, postpartum women were targeted as the consumer sample and 110 (89%) women were surveyed in hospital and 108 (88%) six weeks after discharge. Overall, the obstetric consumer sample rated their care highly, while confidence and trust in the doctor, and satisfaction with information and involvement with decisions, was rated very high. The medical record review revealed that 20 (19%) medical records contained one or more of the technical adverse event predictors (Wilson et al 1996). Consumer satisfaction with communication, information and involvement in decision making processes, was compared to the medical record data, which identified women who did or did not have evidence of technical adverse event predictors. The data comparison identified that a positive satisfaction rating by the consumer did not correlate with either the presence or absence of technical predictors in the medical record. There were no complaints recorded by obstetric participants. There was no statistical relationship between the consumer sample’s age, health insurance and satisfaction with care.

Wilson et al’s (1996) study concluded that consumers were able to discriminate between their healthcare providers, and the healthcare environment. This was demonstrated in the participants reporting being less satisfied with accommodation and cleanliness, than with the information sharing behaviours of their provider, and less satisfied with the availability of nursing rather than medical care. In addition, the likelihood of consumer complaints was low and satisfaction high, even with evidence of a significant number of technical adverse events in the medical record. The lack of a relationship between the technical quality of healthcare and consumer satisfaction or complaint did not support the idea that one measure could be used as a proxy for the other. The authors concluded that a consumer’s retrospective satisfaction with care does not reflect the technical quality of care nor complaints. It was noted that the medical record review provided information, within a clinical context, about
the consumer’s contemporaneous feelings and reactions, which was of use for the healthcare provider and the organisation to review practice.

In their discussion of the findings, Wilson et al (1996) highlight that improving the understanding of the provider and the health services about what satisfies the consumer is likely to facilitate a customer focus to healthcare. Significantly, the consumer’s satisfaction is unlikely to facilitate an improved technical quality of healthcare or the health status of the consumer. This suggests that consumer oriented healthcare and provision of standardised quality healthcare are conflicting agendas facing the contemporary healthcare service. Further exploration of this concept is beyond the scope of this literature review.

What does Consumer Satisfaction Measure?

Like Wilson’s study in 1996, Degeling, Sorensen, Maxwell, Aisbett, Zhang and Coyle took a multi-method approach to studying the organisation of healthcare in 2000. Degeling’s (2000) design integrated three clinical diagnoses across twelve clinical settings located in seven New South Wales health services. The study’s participants were healthcare consumers and included: elective caesarean section (ECS) (n=174); appendicectomy (n= 171); and transurethral prostatectomy (TURP) (n=157) consumers. Analysis of the study’s retrospective survey data highlighted that the ECS respondents (n= 94 or 54%) were more likely to report themselves as being young, healthy individuals, who were not sick and were anticipating a positive outcome to their hospitalisation, than the appendicectomy respondents (n= 77 or 45%) or the TURP respondents (n= 86 or 55%). The authors argued that the ECS consumer sample demographics (i.e. age and gender) favourably influenced their capacity to identify and express their opinions in relation to healthcare, when compared to the other participant’s data. The ECS participants tended to rate the professional competence and health outcome aspects of care highly. Anecdotally, this rating was discussed as being an indicator that the needs of the ECS participants for medical care were met. To the contrary, Degeling et al (2000) also argues that the ECS consumers’ high rating of healthcare quality
on the likert scale was not objective, as the consumers frequently indicated in their open responses that they had made allowances and acknowledged sympathy for the difficult conditions that the healthcare providers worked under. Degeling’s study is Phase One of the Commonwealth project that my study is nestled within.

It is important to note that the literature reviewed thus far has not been able to demonstrate a clear relationship between consumer satisfaction measures and the effectiveness, efficiency and improved health outcomes. Methods of obtaining consumer satisfaction data have been critically reviewed and have been predominantly ad hoc or manipulated for the purpose of the health service, provider or researcher. Examining consumer satisfaction or dissatisfaction within the context of the healthcare experience, as recorded in the medical record, has been suggested as a method of making the consumers’ perception of their experience more useful as a quality indicator for health services.

In the context of the consumer oriented model of healthcare, a satisfied consumer is one who’s perceived needs have been met. In the literature I have reviewed, consideration of what the consumer expects or determines to be a healthcare need or outcome is not included in the design of the studies. The aim of this study is to further understand what consumer satisfaction indicates by comparing the consumers’ level of satisfaction with their involvement in healthcare and the medical record’s description of involvement in decision making and information sharing.

**Factors that Influence Consumer Outcome Measures**

Perception of Control

Perceived control in health related events is an outcome measure that is also considered relevant when seeking to determine the level of partnership in healthcare decision making. England & Evans (1992) have stated that interventions designed to encourage healthcare consumer participation in
treatment decisions are justified; however, accepting an invitation to participate in treatment decisions should not be taken as the consumer perceiving control in relation to the decision making process. This view was based on the responses of 143 consumers who attended a government funded Cardiovascular Risk Management (CRM) Clinic in the Australian Capital Territory. The consumer sample, either medically referred or self-referred to attend the CRM clinic, were each invited to select one of seven behaviours for which the clinic’s 13-week behaviour change treatment would target. The data collected for this study included before and after intervention measurements of blood pressure, body mass index, and a several staged self-report questionnaire. There was no control group to compare findings against.

England & Evans (1992) found that consumers who were doctor or nurse referred tended to choose behaviour interventions that they perceived to be the preference of their provider. Despite the healthcare provider’s claim of not intending to influence the consumer’s choices, the information provided by the provider and the provider’s interests, were found to significantly impact on the choice of treatment. The doctor/nurse–referred consumers also tended to perceive that their control over their health in general was lower than self-referred consumers. Interestingly, even though the study intervention was only commenced and focused on the request of the consumer, some participants reported feeling that they: had not made the treatment decision; had not taken charge of planning; could not be held responsible; and, had not had the ‘last word’. England & Evans (1992) acknowledge that their findings appear to be somewhat matter-of-fact; stating that each consumer holds beliefs on the personal control they perceive they have overall, and that taking the time to coach and build a healthcare relationship between the consumer and provider is likely to have some influence on the consumer’s perception of control. The authors are also pragmatic in stating that the implications to the efficiency of the healthcare system, where longer consultation time and improved access to a diverse range of information sources, are factors to be considered (England & Evans 1992). Anecdotally, the study claims that in subsequent healthcare visits, after relationship building, the consultation did tend to be more
efficient because both the consumer and provider knew what was expected. However, consultation time and efficiency were not measured in the study.

Kaplan’s (1989a) study, whose details were reviewed earlier in this chapter (p.62), found that consumers who had expressed in their healthcare interactions a sense of control and an emotional exchange of opinion with their provider, were more likely to demonstrate stability in physiological measures (e.g. blood pressure and blood sugar control). In contrast, the researchers found that poor diabetes and hypertension control was associated with less evidence of control, effective information seeking, or involvement in decision making by the consumer in their interactions with the provider. Both the Kaplan and England & Evans studies suggest that the perception of control in healthcare related events is linked to the personal control perceived overall by the consumer. The consumers’ perception of control is also vulnerable to the attributes of the provider and environment. Consequently, the numerous factors associated with perceived control in relation to consumer/provider healthcare relationships increases the complexity of using this variable as an outcome measure related to consumer participation in healthcare decision making.

Control in the maternity care relationship has been reported to be multi-dimensional. Based on involvement in studies on women’s expectations, satisfaction and birth outcomes and a review of the literature, Josephine Green (senior lecturer at the University of Leeds, Mother and Infant Research Unit), is of the opinion that control is a core construct of respect. Green (1999) describes respect within a maternity care relationship, as the balance between being supported to exert personal control, and yet being able to relinquish control or decision making responsibility. In this scenario, the woman perceives a sense of control in the decisions her healthcare provider may make. Hopkins’ (2000) Brazilian study, referred to earlier (p.55), used a combination of a postpartum survey, participant observation, interviews and analysis of conservations between the women and healthcare providers as a method to explore the concept of the woman’s perceived equity in power or control in the decision making process. Hopkins (2000) reconstructed and
interpreted the woman’s participation in the decision process at the labour/delivery stage of the pregnancy, and identified that the healthcare providers did not respect the woman. The findings support the view that the doctors in the study manipulated the concept of control. Examples are provided where the doctor prepares the woman to ask for a caesarean, by framing information and risk-ratios in such a way that her concerns and fears are not addressed and caesarean is portrayed as the safest option. As a result, the woman chooses or perceives control over the decision process and the doctor restates that the caesarean is at her request, validating the woman’s perception of control.

The literature review supports the view that a sense of personal control is an influential factor in the healthcare relationship and level of consumer participation activity. It is also evident that issues related to the organisation of care (e.g. consultation time) and information sharing (e.g. increasing scope and credibility of information sources) are also influential factors. The literature also suggests that the perception of control is vulnerable in cases where provider influence may reduce the consumer’s sense of control, or it may even be manipulated by the provider to give a false sense of control. Due to these variables, perceived control as a health outcome measure will not be directly sought in this study; however, the intention of the provider to respect the consumer’s participation will be explored.

Active Patient Orientation

Based on her Doctoral studies Beryl Schulman (1977 cited in Schulman 1979) describes Active Patient Orientation as health services that are oriented to the healthcare consumer as an active participant in treatment, and as a result are capable of influencing treatment outcomes. To meet Schulman’s Active Patient Orientation framework the service must demonstrate three principles:

- Attitudes and expectations communicated to patients by health professionals are supportive of patients’ motivation and ability to contribute to the treatment process and to understand and carry out
treatment recommendations, with active participation reinforced through such means as praise, graphic display of clinical progress.

Illness management is conducted as a collaborative process between patient and health professional, involving two-way communication and joint decision making; patient input is actively encouraged through direct solicitation of information/opinions and responsiveness to questions.

Medical resources are provided in such a way as to insure their usefulness to the patient; that is, explanations are full and clear; instructions are explicitly operationalised; skill training and technical aids are made available to assist self care.

(Schulman 1977 cited in Schulman 1979, p268)

Schulman (1979) examined the link between an Active Patient Orientation (APO) and treatment outcomes in 99 outpatients attending two hypertension clinics over a five month period in the USA. The study participants were also involved in a longitudinal study by Steckel & Swain (1977, cited in Schulman 1979) who were exploring ‘The use of written contracts to increase patient compliance’. Schulman’s (1979) study intended to build on previous research that had established causal links between individual traits and treatment compliance, and aimed to further explore the socio-organisational explanations of consumer participation in treatment. Schulman’s method included an interview, during which the participants completed a 4-point scale (strongly disagree to strongly agree) questionnaire that listed eleven statements constructed and validated from Schulman’s previous APO research (1977 cited in Schulman 1979). Scores were calculated by averaging the responses to the eleven APO items. Treatment outcomes were assessed by monitoring the participant’s blood pressure measurements for the duration of the study and averaging the diastolic pressures. Schulman’s (1979) study identified that higher APO ratings were positively related to the degree the individual’s blood pressure was controlled (favourable treatment outcome). The high rating of
medical care, cognitive outcomes (e.g. perception of being partners in the healthcare processes) and behavioural outcomes (e.g. confidence in their self-care ability) were also favourably associated to the level of APO rated.

Schulman’s (1979) work supports the view that a health service’s capacity to adopt the socio-organisational attributes of APO, is likely to favourably influence the physical, cognitive and behavioural outcomes of the healthcare consumer. This association is of interest to this study as I will make use of Schulman’s APO framework (1977 cited in Schulman 1979) to determine the socio-organisational attributes of consumer participation in the study settings. Each setting’s capacity to support an APO will also be compared with consumer and provider responses. It is considered that this method of review and comparison will assist in determining the level of consumer participation in healthcare decision making at the individual level.

Psychological Measures as Health Outcomes

Fallowfield, Hall, Maguire and Baum (1990) undertook a literature review to explore the concept that consumer choice promoted health sustaining outcomes, and argued that the evidence remains inconclusive. The main reason for doubt was the methodological and data management flaws, such as short term follow-up in small samples and incomplete reporting of data. Fallowfield et al (1990) found that it was a common concern amongst researchers, that collecting behavioural/cognitive measures after obtaining informed consent and randomly allocating consumers into treatment groups is likely to create biased outcomes; with the methodology being more likely to increase anxiety measures than the treatment.

Informed by their literature review Fallowfield et al (1990) then set out to address criticisms of the randomised clinical trial method of previous studies by conducting a prospective, multicentre study of the psychological adjustment of women (n=269) with early breast cancer. The women were referred to 22 different surgeons in 19 different settings. Based on each surgeon’s primary surgical policy for treating early breast cancer, the women
were divided into three groups: surgeons who favoured mastectomy (n=30); surgeons who favoured breast conservation (n=121); and surgeons who offered a choice (n=118). The study aimed to assess the psychological outcomes, such as the level of anxiety and depression, of the different treatment policies for early breast cancer. The psychological outcomes were assessed by validated self-assessment questionnaires and by tape recorded semi-structured psychiatric interviews. Of interest to this study, each surgeon was asked to identify how they decided treatment (i.e. decision based on consumer preference, surgeon preference or for technical reasons). To determine whether the recommended or self determined surgical treatment, of either mastectomy (n=154) or lumpectomy (n=115), had been carried out for the reasons stated, the data was compared and found to be representative of the women’s perception of the treatment decision process and an audit of the hospital notes.

The psychological interviews identified that the women (n=269), irrespective of their treatment, experienced considerable anxiety with no significant difference between the treatment groups. Similarly, 15-29% of women, irrespective of their treatment were depressed. Significantly, the anxiety and depression measures analysed by treatment decisions identified that women who were offered a choice in their treatment decision had a decrease incidence of anxiety and less depression than the surgeon determined treatment groups. Fallowfield et al (1990) suggested that the significant variables that impacted on psychological outcomes were the technique or the skill of the health professional in counselling, information sharing and whether the consumer displayed anxiety as a characteristic trait. The authors propose that what many consumers want is not the ultimate surgical treatment decision, but adequate information comparing the pros and cons of treatment choices (Fallowfield et al 1990).

In the analysis of their prospective study, Fallowfield et al (1990) compared their data to the retrospective data collected from a previous randomised trial which had a smaller sample size. This comparative analysis offered an absence of statistically significant difference between the two studies. Fallowfield et
al’s (1990) findings argue for the introduction of screening systems to identify consumers who are prone to anxiety and are vulnerable to clinical anxiety and depression. Consumer views on information sharing or their capacity to participate in decision making were suggested to be influenced by factors such as: encouraging a companion to attend consultation; taping the consultation; and, providing opportunities to meet with counsellors or specialists to further discuss the consultation.

Screening of psychological measures may therefore be useful in ensuring that appropriate strategies are accessible to maximise the consumer’s participation in healthcare decision making. Facilitating the consumer’s participation in decision making is also linked with minimising the psychological anxiety associated with healthcare. This outcome will not be directly sought in this study. However, I find it reassuring to consider that in facilitating consumer involvement in healthcare decisions, it is likely to minimise psychological stress such as anxiety and depression, two factors that are frequently linked with caesarean section and early motherhood.

Self-Efficacy

The potential influence of self determination on sustainable health outcomes, improving behaviours and reducing healthcare expenditure, motivated Lorig and colleagues (1999) to undertake a study to measure the effectiveness of a self management program for a heterogeneous group of chronic disease consumers, with the outcomes being changes in health behaviours, health status and health service utilisation. The study design was a randomised controlled trial at community based sites, comparing treatment subjects (n=561) with wait-list control subjects (n=391). The self management program was based on Bandura’s (1977 cited in Lorig et al 1999) self-efficacy theory\(^1\) and included seven weekly, two and a half hour sessions. The sessions were facilitated by a trained lay instructor and included action planning and

\(^1\) Self efficacy is the expectation that one is sufficiently competent to perform a behaviour, it predicts both intention and behaviour.
feedback, modelling of health promoting behaviours, communication skills, problem solving and decision making techniques.

The findings report that 84% of treatment participants completed the six month program and attended an average of 5.5 of the seven sessions (Lorig et al 1999). The treatment program was provided at an organisational cost of $70 per participant. Through the analysis of a self-report questionnaire, administered prior to the intervention and six months after, improved health behaviours and status were reported together with reduced service utilisation and hospitalisation. In addition, there was a health expenditure saving of approximately $750 per participant. These measures represent, in an empirical format, the propensity for improved health outcomes from descriptive studies of consumer participation in individual care (CFC 2001).

**Methods of Measuring Consumer Outcomes**

The assumption that interpersonal aspects of healthcare influenced consumer satisfaction and healthcare outcome measures, led two UK researchers Mead and Bower (2000) to complete a comprehensive review of methods used in the empirical literature to capture the participative attributes of the healthcare relationship.

**Self-Report Measures**

Mead and Bower (2000) found that the self-report method was fraught with reliability issues and should not be used uncritically as a *gold-standard*. A summary of the issues include: inventories that reflect a broad range of issues were aggregated when scoring scales; over time the methods were marginally insensitive to change; construct validity was influenced by external variables such as gender, culture and demographics; and, responses were framed in a socially desirable format (Mead & Bower 2000). A positive aspect of the self-report survey was minimal cost because a large representative sample could be accessed and the instruments were easy to administer and analyse.
External Observation Measures

External observation methods were found to predominantly employ rating scales that categorised how much or how well a specific behaviour was performed or a verbal behaviour was expressed. These elements may have been rated individually or in combination. In their research, Mead and Bower (2000) critically reviewed the content, reliability and validity of six different scales. Some of the issues identified were: the ambiguity in the clarity of the processes being rated; multiple dimensions being represented by a single measure; and tendency for low to moderate inter-rater reliability reported when interpreting subjective data. This method was also criticized for the small sample sizes, and for being time, experience and resource dependent.

Application of Measures

The methodologies reviewed in the literature by Mead and Bower (2000) was limited as they tended to capture a single interaction, rather than the dynamics of developing a relationship over a particular time frame. Other limitations were the inability of individual providers or consumers to reflect on or modify practices and behaviours due to the tendency to aggregate the data and then lose the personal attributes of the data. Mead and Bower (2000) suggested using the self-report and observational methods to compliment inter-personal process recall and inform peer and self review strategies, such as post-consultation interviews. Mead and Bower’s (2000) literature review supports data triangulation (i.e. doctor, patient and external observer) rather than focusing on one data source and is significant to this study because triangulation is the approach used for this study.

Section Four Summary

In this section of the literature review, participation in individual healthcare is shown to be a multidimensional concept that can be measured by perceived experience (satisfaction/dissatisfaction survey), observation of the experience (behaviours, verbal, documented), environmental conditions (level of activity,
orientation, processes) and enhanced by preparing the consumer, provider and organisation for the healthcare experience. It is implied, but not verified, that obtaining outcome measures is a useful mechanisms for professional and organisational monitoring of healthcare quality and responsive to the needs of their service community.

Based on the literature reviewed, I assert that Bastian’s (1996) levels of consumer participation framework warrants further exploration. Bastian’s framework is supported by Schulman’s (1979) work, who claims that health services that adopt the socio-organisational attributes of Active Patient Orientation (APO) are also likely to influence the physical, cognitive and behavioural outcomes of the consumer. Both Bastian’s and Schulman’s work is relevant to this study, because I endeavour to determine the socio-organisational attributes of consumer participation in the study settings. Each setting’s capacity to support an APO, will be compared with the consumer and provider responses. It is considered that this method of review and comparison will assist in determining not only the level of consumer participation in healthcare decision making at the individual level, but also afford discussion on relevant healthcare outcomes associated with an active level of participation.

Consumer satisfaction is presented as a subjective, unreliable measure that lacks scientific credibility. Securing consumer satisfaction with healthcare is also stated as being unlikely to facilitate an improved technical quality of healthcare or the health status of the consumer. In acknowledging these limitations this study explores the consumer’s healthcare experience as multifaceted, measuring satisfaction as just one measure that should be examined together with other outcome indicators.

In exploring the concept of a consumer oriented model of healthcare, a satisfied consumer is one who’s perceived needs have been met. In the review, previous studies have not included or considered the consumer’s expectation or perceived healthcare needs as influential on satisfaction measures. One aim of this study is to further understand consumer satisfaction by comparing the
satisfaction data with the consumers’ expectations and with their medical record contents. I will determine the level of consumer inclusion in healthcare decision making and/or information sharing by reviewing each consumer’s medical record.

By taking a broad sweep of the consumers healthcare experience, I expect to be able to identify some of the diverse issues (i.e. respect, flexibility, organisation of care, scope and credibility of information sources, psychological screening) raised in the literature as influential on health outcomes. The review also suggests that taking a triangulated approach to determining healthcare outcomes, including the perspective of the provider, consumer and an external observer, whilst also collating qualitative and quantitative descriptions of the process, will improve the reliability and usefulness of the study data.

The medical records role in the consumer/provider healthcare experience and its potential as an outcome measurement tool will now be reviewed.
Section Five: The Medical Record

Consumer participation is shown in this literature review to be a multidimensional concept that incorporates the key components of decision making and information sharing. The dynamics of the consumer/provider relationship have been reviewed in the context of the environment, the structures, process and the individuals involved. Measuring participation as an outcome has been found to require representation of each of the aforementioned elements. Methods of capturing or reconstructing the consumer/provider relationship have had commonality in that they have analysed directly or indirectly the communication or interpersonal qualities of the relationship. This section of the literature review will explore healthcare documentation and its capacity to reflect accurately the individual’s healthcare experience.

The Role of the Integrated Medical Record

The medical record is a multifunctional source of observation, communication and information in a documented format (Radcliffe 1999). The record can potentially supply data about the individual consumer’s health history, previous hospitalisation, past experiences with the healthcare system, and observations that others have made. The record can provide consistency of care and indicators of additional sources of information, such as other healthcare providers or services that have cared for the consumer (Rankin 2001).

Traditionally, documentation of hospital healthcare was a segregated process, with medical, nursing and allied health providers documenting and storing their records separately. Only recently has the record become an integrated document (Page 1999). This integration reflects healthcare trends where the healthcare consumer is likely to interact with multiple providers who specialise in specific fields. Each provider contributes to the consumer’s healthcare from a different area of professional competency. It has been suggested that integrated medical records have addressed the inter-professional
communication and coordination deficits between providers; therefore, improving communication with consumers and their satisfaction with healthcare (McKenna 1995).

Guidelines and Medicolegal Implications of Documentation

Health departments recognise the importance of the medical record and have produced guidelines that state:

..the health record shall be started and maintained for every person receiving healthcare services in a hospital, nursing home, community health centre or other healthcare facility. Health records must be kept confidential, accurate, complete and readily available for patient care (NSW Health 81/218 cited in Berglund, 1998 p 55).

Legal issues also regulate the principles of documentation in the medical record. All medical, nursing and health provider records are potential legal documents (Jamieson 1999). In Australia, Freedom of Information legislation has also granted the patient/consumer access to their medical records if held in public institutions. Interestingly, this does not apply to private hospitals or doctors in private practice unless the consumer is undertaking legal processes (Jamieson 1999).

Recent interest by health services in adopting the consumer oriented model implies that the consumer is increasingly aware of their rights and has expectations of the service. In this context, it has been suggested that the dissatisfied consumer (i.e. one whose expectations had not been met) is likely to perceive it is their right to question service quality and outcomes. On behalf of a consumer a lawyer may pursue a claim of medical negligence. This means that every document that forms part of the consumer’s record is made available for scrutiny, and may be used as evidence. In the legal arena, if an event or action is not documented in the record, then it did not happen. Conversely, if the documentation is detailed, timely and accurate, the investigation may be abandoned (Jamieson 1999). It has been noted amongst
health providers that the main purpose of documentation has shifted from responsibility of care, to “covering your back” in case of future legal action (Radcliffe 1999).

Another significant consequence of poor documentation practices, particularly for nursing and midwifery professionals, is the potential for disciplinary action by employing organisations and/or nursing registration bodies (Jamieson 1999). Curiously, medical practitioners are often not employees of the hospital and have a completely separate line of authority and generally act independently of the hospital administration (Bishop 1994).

In principle, the integrated medical record is a rich source of reliable and accessible data in relation to the individual consumer’s healthcare experience. The legislative changes that have accompanied the shift towards the consumer oriented approach to healthcare, has meant that the medical record content is now open to scrutiny by the consumer, as well as the quality of the documentation being open to scrutiny by legal, employer and professional groups. This suggests that health providers would be motivated to ensure the content and the quality of the medical record met legal requirements. It is suggested that nurses or midwives may be more accustomed to such scrutiny, than their medical counterparts, and therefore more proficient at documenting healthcare adequately. These issues are of particular interest for this study, where the medical records contents will be scrutinised for its completeness and its capacity to be representative of the consumer’s experience.

**Medical Record Content**

The medical record, as an accurate and complete record of healthcare, purports to contain the most complete chronological documentation of observations, interventions and outcomes. Structured reviews’ of the medical record has contributed to healthcare quality assurance and research efforts, supporting the suggestion that record keeping quality is a reflection of medical care quality (Wilson et al 1995; AHMAC 1996; Wolff 1996).
Caesarean Record Content Audit

In 1998 four doctors, Roach, Lau, Ngan Kee and Wormald, carried out a retrospective analysis of caesarean section operative (n=104) and anaesthetic records (n=101) in a large teaching hospital in Hong Kong as a means to assess the record’s content and accuracy. Caesarean section records were chosen because it was a common procedure involving a relatively consistent operative and anaesthetic technique and had a high litigation potential. They retrospectively explored the deficiency in documentation in the medical record by examining: the duty of care; clinical management; and, litigation consequences. As there were no guidelines available for surgical documentation in obstetrics, the criteria stipulated by the Australian and New Zealand College of Anaesthetists College Policy Document was the basis of designing a modified checklist http://www.medeserv.com.au/anzca/open/p6_1996.htm cited in Roach et al 1998).

Each operating record (n=104) was audited for information in twelve different categories, the information was classified as either: 1. Complete, fulfilled all criteria; 2. Incomplete; 3. Incorrect, if it contained any wrong information; 4. Absent, if the relevant information was not present; and 5. Illegible. The audit identified that seventeen of the operative records were classified incomplete for patient identification (i.e. name and hospital identification number) and date of operation (i.e. day, month and year). Only four (3.8%) records included the operating time (i.e. commencement time, finish time and total duration). Documentation of the woman’s previous abdominal surgery in the operative record was absent in 22 of 35 records (63%). Incomplete information on skin closure was classified in 63 (60%) records. The anaesthetic record (n=101) review indicated that documentation was most likely to be inadequate in relation to airway (87%) and anaesthetic positioning (82%) information, followed by post-anaesthesia plan (70%) and results of pre-operative investigations (69%).
In discussing their findings, Roach et al (1998) are pragmatic in stating that the record audit suggests a reckless indifference to documentation standards and indifferent to litigation. The authors also state that it is unlikely that the inadequate documentation will be the cause of litigation; it is the inadequate quality of healthcare or adverse outcome that results from the documentation that is the issue. The implications of making clinical decisions for anaesthetised patients who are inadequately identified and whose surgical history and pre-operative investigations are incomplete are obvious.

Roach et al’s (1998) findings are somewhat disconcerting, and are not only relevant to their study, in fact the quality of medical record documentation across the UK is comparably poor. Jane Cowan (2000) argues that from her experience as medico-legal advisor to the risk management unit of the Medical Protection Society, Leeds, UK, the clinical documentation reviewed for risk management purposes revealed that good documentation practices remain far from universal.

Documentation, Communication and Collaboration

Documentation in the medical record can only be an effective form of communication if the message conveyed or recorded is accessible, complete and understandable to the intended receiver (Roach et al 1998). The Cochrane Library’s systematic review of the effects of interventions designed to improve nurse-doctor collaboration suggested that strategies that improved communication were likely to improve cooperation between providers, and as a result improve healthcare processes and outcomes (Zwarenstein & Bryant 2000). ACSQH (2000) reiterates that their intention of addressing issues such as legibility, complexity and portability of the medical record, will go some way to facilitating collaboration between healthcare providers. ACSQH (2000) consider collaboration between providers to be a prerequisite to provider/consumer sharing the responsibility in achieving health outcomes, and the provision of safe, high quality healthcare.
Despite the literature suggesting that improved communication will lead to collaboration and improved health outcomes, the Cochrane review also concluded that further research was needed. Limitations in the literature included the complexity and numerous variables used to measure the effect of provider collaboration, and the size and diversity required of the sample (Zwarenstein & Bryant 2000). The reviewers suggested that a multi-centre approach would be recommended; the paradox being that this approach would be dependent on provider collaboration. The Cochrane review findings also suggested that prior to commencing any further intervention research, consideration be given to identifying and collating the perceived and structural barriers to provider collaboration (Zwarenstein & Bryant 2000). This raises the question as to the likely effectiveness of any intervention endorsed by the ACSQH (2000) to address communication issues, particularly issues related to the medical record, if the specific barriers to collaboration have yet to be identified.

Portability and Legibility of the Medical Record

In contrast to the limited research available on either identifying barriers or measuring the effect of interventions to improve collaboration, outcomes related to improving the portability and legibility of the medical record and hence the effectiveness of communication have been reported by two UK studies (Draper et al 1986; Elbourne et al 1987). The studies explored women holding their own maternity care medical record. The previous system of multiple records and cooperation cards had been suggested to be an ineffective form of communication and inefficient use of resources. The outcomes of these studies were also supported by more recent research, which found that women who held their full maternity care records were more likely to feel in control of their antenatal care, and perceived it easier to communicate with doctors and midwives (Elbourne et al 1987; Webster et al 1996).

The literature identifies that the most consistent and important predictor of the quality of maternity care documentation, is the use of the printed form
(Adeyi and Morrow 1997). The provision of prompts within a printed form is linked with the probability that the healthcare provider will understand, perform and document tasks. One specific advantage of a formatted document, in maternity care, is the capacity to monitor and manage maternal and fetal development data (Hofmeyr 1994). Therefore, access to portable formatted forms that detail maternity care progress, allows the woman to move from one facility to another during her pregnancy, whilst still maintaining a form of continuity of care with her provider. This is likely to influence not only the quality, but also the safety, of maternity care (Hodnett 2002).

There was no evidence of negative effects in any of the studies reviewed in relation to improving the portability of the medical record. However, they did demonstrate commonality in finding that women had more difficulty in understanding the legibility of the notes rather than the content (Draper et al 1986; Elbourne et al 1987). A decade later, John Cabral is of the opinion that illegible medical documentation continues to impede not only consumers’ cooperation in their healthcare, but also the: consumers’ participation; the communication between healthcare providers; and, the quality of healthcare (Cabral 1997).

Consumer Held Record and Positive Health Outcomes

A stratified randomised controlled trial of women attending an antenatal clinic at an Australian tertiary referral hospital found that women who carried their maternity care record, in comparison to those who did not, were more satisfied with their experience and reported higher scores for three elements of satisfaction: 1. Information giving; 2. Participation in decision making; and, 3. Relationships with caregivers (Rowley et al 1995). The 1999 Senate report also recommended that a woman held, portable record was an effective means of addressing the dissatisfaction women have expressed with the discontinuity of provider that has developed in some models of shared maternity care.

The Cochrane library protocol, ‘Giving women their own case notes to carry during pregnancy’ (Brown 2002), reported that based on the best available
Evidence, women carrying their own case notes was likely to positively influence the clinical environment by: improving access to records; reducing potential adverse events through transcribing errors and segregated notes; whilst also being cost effective. Health outcomes that have been associated with the practice of women carrying their antenatal records include reports of greater consumer participation in medical care decision making (Webster et al 1996; Homer et al 1999) and having a favourable influence on maternal behaviours, such as reduced smoking and improved breastfeeding rates (Brown 2002).

Communication Behaviours in the Acute Hospital Setting

It has frequently been reported that different healthcare professions have different interests, priorities and perspectives (Page 1999), and that each profession has evolved ways of organising and ways of communicating what they do because of cultural differences (McKenna 1995).

Healthcare Provider Communication Behaviours

Degeling, Kennedy, Hill, Carnegie and Holt’s (1998) study aimed to assess to what extent healthcare providers and their managers had adopted recent hospital reform strategies. They suggested that a commitment to standardising work practices, a transparent approach to clinical management accountability and acceptance of healthcare resource rationalisation indicated that the healthcare provider had adopted the reforms. Six hospitals were surveyed (two Australian and two English teaching hospitals, and two English district hospitals). A closed questionnaire was distributed to cluster samples of healthcare providers (n=856). The survey’s findings identified that distinctive professional subcultures were evident in the medical and nursing clinician samples irrespective of the hospital setting. Medical clinicians were characterised by individualistic opinions in contrast to the institutionalised collective opinions of organising clinical work amongst nurse clinicians. The distinctive characteristics of the professional subcultures were so significant that a respondent’s occupational background could be determined with a high degree of confidence because of the attitudes, beliefs and values of the
respondent (Degeling et al 1998). These differences were argued by the authors to be a major contributing factor to the fragmentation of healthcare found across the study sites (Degeling et al 1998).

Degeling et al’s (1998) findings also reflected other research findings, such as the suggestion that consumers generally do not experience poor quality care within a single discipline, but at the boundary of care between disciplines (McKenna 1995). Hugh McKenna’s double-blind reviewed discussion paper outlines the significance, and the barriers, towards adopting a multi-professional approach to clinical audit (1995). He describes healthcare as the ocean, and the different healthcare providers as ‘inhabitants’ of different islands, displaying different languages and culture. The healthcare consumer originates from yet another island, and is required to decipher the language and beliefs of the healthcare providers they meet on their journey. This description suggests that a significant disparity between the views and the communication behaviours of the healthcare providers is inversely proportional to the quality of healthcare and the consumer’s perception of being able to participate in healthcare decision making.

A further barrier to effective communication within healthcare and between healthcare providers is the preference for communication methods that are known to be inefficient. Reviewing recent research, Parker & Coiera (2000) identified that healthcare providers favoured traditional forms of communication, such as telephone calls and chance face to face meetings rather than standardised or documented forms. Parker and Coiera (2000) examined these preferences from a cognitive psychological perspective, taking into consideration what is known about human memory functions and what effect constant interruptions have on the ability to work effectively. As a result, the healthcare providers’ traditional communication behaviours were described as being conducive to promoting highly interruptive working environments and increased potential for clinical errors, resulting in inefficient clinical communication behaviours that prohibit effective communication in hospital settings (Parker and Coiera 2000). In the context of this study, healthcare provider communication behaviours have been linked to
the environment's capacity to support active participation by the healthcare consumer and therefore deserve to be considered in this study's design.

Documentation as Communication Behaviour

Communication is a core component of healthcare. In this literature review, healthcare has been discussed as transitioning, with some resistance, from the traditional towards a contemporary method of service delivery. It would not be presumptuous to assume that the way healthcare providers communicate is also changing. Documentation is a common form of communication, with over a sixth of a provider's work time, particular a nurse's work time, reported to be dedicated to documenting (Devlin et al 1999). Compared to their medical colleagues, nurses have also taken the most interest in improving the current methods of documentation and critically reviewing their documentation practices (Seldon 1999; Currell et al 2001; Degeling et al 2000).

Healthcare, as a contemporary service, is not immune to the demands of increased productivity, and to meet these demands many healthcare records are now designed with a simple tick box format to maximise time-efficiency. Another feature of contemporary healthcare is the number and diversity of providers that contribute to service delivery, and to promote consistent documenting practices amongst a constantly changing workforce the healthcare forms are accompanied by explanatory guidelines (Pilgrim and McNeil 1999). Another strategy to improve communication between the health service, multi-discipline providers and the consumer is the development of clinical or critical pathways (Page 1999).

Clinical Pathways as a Standardised Form of Communication

In outlining the future directions of nursing documentation, Chris Page (1999) claims that the clinical pathway is an instrument that has the propensity to support a consistent standard of care, promote meaningful documentation and be a mechanism for cost and quality control. The clinical pathway is intended to identify the core healthcare components as well as the progressive daily
requirements of the consumer, thereby moving the individual in a timely and coordinated fashion towards discharge. Pathways have been developed in various formats, some allowing for direct clinical documentation, others as a structured plan with individual care documented in the medical record. However, it is important to note that the capacity of the clinical pathway document, irrespective of its format, is highly dependent on a standardised, collaborative and timely approach to planning, providing and documenting healthcare (Moorhead et al 1998).

In Phase One of the Commonwealth project, *The Organisation of Hospital Care and its Effects*, Degeling et al (2000) predicted that it was likely that the delivery of high quality and cost efficient healthcare would be associated with the multidisciplinary institutionalisation of the clinical pathway concept as the standardised form of communication. For the clinical pathway to have this effect, it was recommended: a clinical pathway would be commenced when the consumer first contacts the health service; it followed the trajectory of care, including variance analysis; and, it included the availability of a patient information pathway, mirroring the clinician’s pathway. Page (1999) describes variances in the trajectory of healthcare, as any *deviation* from the anticipated care path outlined in the clinical pathway. Provision to *flag* or record variances from the pathway, be they positive, negative, avoidable or unavoidable deviations or variances from the anticipated care path, is imperative. Effective coordination and communication of an individual’s healthcare needs, is dependent on the contemporaneous review of variations within the individual context of the consumers’ healthcare experience (Page 1999).

In regard to maternity services, Driscoll and Caico’s (1996) review of clinical pathways that coupled mothers and babies, reported that the midwives considered the pathways to be a *workable form* of documenting care. Consumers reported it to be beneficial that the pathways’ have the capacity to predict standardised care, yet their individual care needs are considered. The absence of health provider accountability, skill deficit in application, and avoidance of standardised language across health disciplines have been cited as common issues that have been reported to have adversely influenced a clinical
pathway’s overall effectiveness (Moorhead et al 1998). The impact of clinical pathways on healthcare quality has been corrupted by issues with implementation, such as the absence of co-ordinated and collaborative approaches within and across healthcare disciplines, and the lack of organisational commitment to reviewing documented practice variations across services (Robinson & Compton 1997; Degeling et al 2000). In relation to this study, the literature suggests that despite a propensity for clinical pathways to improve healthcare quality, there appears to be a lack of consensus or commitment across disciplines as well as an absence of organisational leadership in the development, implementation and evaluation of the clinical pathway. These issues are somewhat reminiscent of the issues discussed earlier in the literature review, where an ad hoc approach to adopting the consumer oriented model as the framework for contemporary healthcare was discussed.

Medical Record as a Source of Quality

The reason for undertaking this study was to gain a greater understanding of consumer participation at the individual level of healthcare. The level of consumer participation activity has been reported as impacting on the quality and safety of healthcare. Despite universal acceptance of this association, researchers have had difficulties in substantiating the rhetoric. Attempts to capture the diversity of the participation experience or determine reliable mechanisms to identify or measure meaningful outcomes that can be associated to consumer participation at the individual level of healthcare have been somewhat ineffectual. For this study, the literature related to auditing medical record documentation will be reviewed for its reliability in predicting healthcare quality, and also its reliability in determining the level of consumer participation in healthcare.

Documentation as a measure of medical care ‘quality’

Determining ways to measure quality and safety outcomes at the frontline of Australian healthcare has been a challenging and confronting task. Healthcare organisations have struggled with defining quality medical care outcomes since
the early 1980s (Wolff 1996). A breakthrough was made in 1995, when a study designed to measure and monitor the technical or clinical aspects of healthcare practices in twenty-eight hospitals in New South Wales and South Australia (Wilson et al, 1995), adapted an organisational peer review process (Brennan et al, 1991) used in the United States of America. In this study potentially adverse events associated with healthcare management resulting in disability or a longer hospital stay were classified and measured. An unintended outcome was an emergent relationship between litigation, cost and the quality of healthcare. They also revealed that adverse events were associated with human and system based factors that were resource draining and yet potentially preventable.

Wilson and colleagues (1995) designed and used a quality improvement methodology that measured preventability, rather than determining negligence and casting blame. The clinical evidence was obtained by a retrospective medical record review as this was considered the best single source of quality information, because it combined the clinical context, the care provided and patient outcomes over time (Wilson et al 1995). The audit method required the medical record to be screened by trained nursing clinicians to identify documented evidence that fulfilled eighteen explicit criteria. The criteria were specifically designed to indicate the possibility of an injury or adverse event caused by the healthcare experience. Medical records that were screened positive were further screened by up to three medical officers who had to reach agreement that an adverse event had occurred.

From the 14,179 admissions to the twenty-eight study sites, 6,200 medical records were initially screened positive for one or more of the eighteen criteria and 2,353 records where confirmed to include an adverse event. The main findings of the study were that 16.6% of admissions were associated with an adverse event and of those admissions, half (8.3%) of the adverse events were judged to have been highly preventable. Interestingly, in comparison to other medical specialities, obstetrics or maternity care were reported to have significantly lower proportion of adverse events. In the analysis of the causes of the adverse events from the Quality in Australia Health Care Study, it was identified that adverse events associated with human error such as ‘decision
making' problems or a failure of 'cognitive function' were generally associated with increased preventability. These errors included ‘failure to synthesise, decide and/or act on available information’, ‘failure to request or arrange investigation, procedure or consultation’, and ‘Misapplication of, or failure to apply, a rule; or use of a bad or inadequate rule’ (Wilson et al 1995 p.468-71). Errors of omission (52% of adverse events) were almost twice as common as errors of commission (27% of adverse events) (Wilson et al 1995).

The study recommended that the medical record review be integrated as an appropriate tool in conjunction with review, analysis and action, within a quality framework. Wilson’s study, although comprehensive, was criticised for requiring substantial resources in time and money. The methodology has since been replicated in national and international studies (Wolff 1996; Wilson et al 1996, Degeling 2000). A drawback of Wilson’s original study (that was not obvious at the time), was that the enormities of the research findings were far beyond the capacity of the healthcare systems’ quality structures to address.

Applying the Research to Clinical Practice

In 1999 Ross Wilson and colleagues completed a secondary analysis of the causes of adverse events from the 1995 Quality in Australian Health Care Study. This analysis was designed to assist healthcare providers and organisations determine the potential underlying causes and develop strategies in order to minimise the occurrence of future adverse events (Wilson et al 1999).

This analysis identified that the medical record documentation as a data source had a number of limitations. Firstly, the record was limited to the context of the individual consumer; secondly, it focused on the actions or interventions of clinicians in direct contact; and, thirdly it under-reported the contribution of other staff and systems with a more supportive role and previous medical/hospitalisation history of the individual (this was only accessible if the consumer attended the same hospital on every occasion). The analysis also indicated that the cognitive or technical performance of the individual provider was influenced by the: (in)adequacy of documented information at
the time of decision making; the individual’s work-load patterns and level of fatigue; and, a minimal level of supervision of junior staff (this was indirectly associated to medical practice culture). The combination of these resulted in an increased error rate and manifested in a system that was not protective of the consumer (Wilson et al 1999).

In relation to this study’s purpose of determining the level of consumer participation at the individual level of healthcare, the limitations stated by Wilson et al (1999) supports the use of the audit methodology. Consequently, the ability to frame the context of healthcare at an individual level and focus on the actions or interventions of clinicians in direct contact with the consumer through auditing the medical record contents is significant for this study. Furthermore, this limitation also supports the intention of only comparing the views and behaviours of clinicians who were identified in the medical record with the data that is collected from the medical record.

The literature suggests that the medical record is a valid and accessible tool, capable of routinely and continuously monitoring the quality of healthcare and is the best available measure of safety in the hospital system (Wilson et al 1995). The Taskforce on Quality in Australian Health Care (1996) has reiterated that the medical record is the most complete, chronological documentation of healthcare. Variations of Wilson’s medical record audit methodology now feature in healthcare research and many reforms have been informed through such quality audits. These findings support the view that, based on the individual’s medical record contents, a reliable quality measure can be made of the consumer’s healthcare experience.

**The Medical Record as a Source of Data in Health Research**

The literature review has demonstrated that utilising the medical record as a data source is popular in health research, yet it is not without its limitations. Aaronson and Burman addressed a number of these limitations in their article, *Use of Health Records in Research* (1994). They viewed the medical record as essentially a documentation of past events, they describe the contents as
already once removed from the actual event, and the data extracted from the record is one step further removed. A number of factors were stated to potentially impact on the reliability and the validity of the record, including: the clinical competence of the recorder; consumer co-operation and competence; type of provider; setting of care; situational factors; and, type of data. Aaronson and Burman (1994) purport that taking and recording healthcare history requires accurate recall from the consumer, competent interviewing skills by the clinician, as well as accurate transcribing skills. Consequently, healthcare records are vulnerable to validity and reliability discrepancies.

Validity, Reliability and Interrater Reliability of Medical Record Data

Aaronson & Burman’s (1994) critical review of the use of health records in research identified correlations between the consumers’ recall of their healthcare experiences and the health records’ documentation to be consistently high in relation to diagnosis, diagnostic tests, major problems and treatment aspects of healthcare. They also commented that the recordings of normative or minor events were frequently missing, indicating a reliability problem if such data was to be sought exclusively from the medical record. Aaronson (1990 cited in Aaronson & Burman 1994) claims that in relation to maternity care, the comparison between the recording of routine obstetrical data in the medical record and consumer recall is likely to demonstrate higher interrater reliability than other medical specialities. It also claims that midwifery documentation was more likely to be present, whilst obstetrician documentation was more likely not to include complications or incidence of problems. Aaronson’s 1990 study methodology was not detailed in the Aaronson & Burman (1994) review.

In exploring consumer recall accuracy, Aaronson & Burman (1994) identified that in some cases consumer recall was influenced by: the type of information being sought; the consumers’ medical condition and cognitive state (influence of hypnotics/tranquillisers, anxiety); and the time frame since the event. However, they also found literature that contradicted the influence of these
factors on consumer recall. Interestingly, Macintyre (1978 cited in Aaronson & Burman 1994) claimed that clinicians adapted the content of their questions based on their perception of the consumer’s capacity to respond. This approach to questioning has obvious potential to influence comparisons between consumer recall accuracy and the consumer actually having been asked a standard clinical question. Clinicians also reported infrequently documenting what they considered to be sensitive information. This means that information such as physical and sexual assaults, alcohol and substance abuse discussed with the consumer were unlikely to be found in the health record.

Health records used in research are often criticised for being subject to systematic and random errors, in both the original records, and in the data extracted from the records. Assessing health record data reliability and validity is complicated because the individual recording the information is in many ways the measuring instrument. Reliability in healthcare record data is often described as interrater reliability; where a measure of reliability is determined by comparing the data recorded by independent providers, trained in using the same tool, who have viewed the same data source, under the same conditions (Aaronson & Burman 1994).

Validity is described as being dependent on construct validity, which is the measure of how a concept behaves in relation to measures of other concepts, given certain theoretically derived hypotheses about the concept being measured (Aaronson & Burman 1994). Potential researchers are warned that health documents are social products and can reflect socially organised or institutional practices. The record constructs a documentary reality devoid of environmental constructs and practice omissions, either intentionally or unintentionally (Atkinson & Hammersley 1983). This has significant implication when attempting to determine the validity or truth of what is actually recorded. Furthermore, if the intention is to capture the dynamics of a social relationship, such as an individual’s participation in healthcare, these findings suggest that as a potential data source the medical record is limited. In order to recreate the constructs in which the data was recorded, the social aspects (environmental and human constructs) that are not documented need
to be considered. This supports the need to triangulate methodologies, collating data that can be considered representative of the environmental and practice considerations that are influential components of the participation relationship. This understanding of the reliability and validity of medical record data is instrumental in considering the appropriate methodology for this study.

**Section Five Summary**

This final section reviewed the role of the medical record in the healthcare experience. Documentation has emerged as a form of social, professional and organisational communication. Issues related to access, legibility, completeness and legal requirements have been explored. Documents that display standardised prompts, reflect the anticipated trajectory of care, include a capacity to record variances and are held or accessible to the consumer and provider alike (such as women held maternity records and clinical pathways), have been reported to have improved the effectiveness of communication within the context of healthcare. Evidence of multidisciplinary and organisational commitment to the development, use and evaluation of such documents have also been favourably linked to the quality of care, the consumer’s satisfaction with care and the attainment of positive health outcomes.

The medical record is reported to be unique in being the only collective statement of what the healthcare organisation and providers do to and for the consumer. It is also described as the only *defensible* link between all factors and persons that affect the healthcare consumer, whilst being the only official record of the outcome of that service (Wolf 1985).

The medical record audit as a measurement tool is shown to be both an effective method of appraising the quality of clinical and technical healthcare (Wilson et al 1995; Roach et al 1998) and useful in validating the reliability of other quality assessment strategies, such as consumer or provider questionnaires (Cleary et al 1989; Wilson et al 1996; Degeling 2000).
In exploring the concept of using the medical record documentation as a potential source of the level of consumer involvement in healthcare (in particular decision making and information sharing), the literature suggests that if such evidence is to be found, then the obstetric medical record is more likely than other specialities, to include such evidence. The literature indicates that an audit of obstetric medical records for adverse events will be less likely to include evidence of preventable events associated with clinical decision making (Wilson et al 1995). This implies that either, the documentation of decision making is more comprehensive in obstetrics than other specialities, or that the threat of medicolegal consequences associated with poor quality documentation (in particular documenting clinical decision processes and events) is more influential on the documenting behaviours of obstetric clinicians than colleagues from other specialities. It is also suggested that the level of agreement between consumer recall accuracy and the health record’s documentation is higher for routine obstetric information than other medical specialities (Aaronson & Burman 1994).

The literature pertaining to the usefulness of the medical record contents and the medical record audit methodology in healthcare research have both been critically reviewed. In planning to use a medical record audit in this study, the literature suggests factoring in mechanisms to ensure the reliability of any data collected. This includes designing a standardised tool for collecting audit data and using validated criteria to categorise the record data. It is also preferable that an independent auditor reviews the same records, under the same conditions, and that the data be compared with that collected by the researcher.

In order to improve the validity of any data audited from the medical record, the literature suggests that one way is to recreate the social constructs in which the documentation took place. It is claimed that the record is only capable of framing the direct experience of the individual; however, the indirect, yet significant influence of environmental issues, professional subcultures and organisation of care (attributes that are required to meaningfully understand the consumer’s involvement in their healthcare), are not able to be
captured through record audit alone. To overcome this limitation and ensure a more holistic approach to determining the level of consumers’ participation in their healthcare, a triangulated approach to the study is recommended.

This approach should include an exploration of the communication behaviours of the provider’s central to the organisation of the consumer’s healthcare; which in this study means, nurse/midwives and doctors in the maternity care setting. More specifically, in order to capture the context of the consumer’s individual experience, the literature suggests exploring the views and behaviours of those providers in direct contact with the consumer; identifiable in the medical record. Reviewing the format and multidisciplinary structure of the documents designed to communicate the consumer’s clinical care is also considered by taking this triangulated approach to determining the consumer’s participation in healthcare. This approach will improve the capacity to interpret the medical record audit data within the context of the consumer’s healthcare experience – which is the aim of this study.

The following literature review summary will draw together the key findings from each of the five sections and will then lead on to the methodology of the study.
Summary of the Literature

This review aimed to explore the literature relating to the broad topic of consumer participation in healthcare, whilst focusing on the themes central to this study; that is, consumer participation in the maternity healthcare environment, in particular participation in planning and delivery of ECS related healthcare. To achieve this, the review has been divided into five sections.

In order to understand the context of consumer participation in healthcare, the first section examined the generic or macro concepts relating to the organisational and social structures in which this study is set. In accordance with the absence of empirical evidence or reliable measuring tools, the literature reviewed was mainly descriptive and opinion based.

The review highlights the absence of understanding or agreement as to what can be considered defining characteristics of consumer participation in healthcare. In addition, there is little acknowledgement of the significant implications for the existing organisational and social systems of healthcare regarding the adoption of a consumer oriented approach to healthcare. Despite these limitations, national and state governing bodies continue to pledge commitment, and direct their subordinates to reorientate service delivery to the consumer oriented healthcare model.

It is a common opinion within the literature that a lack of preparation or initiative has adversely impacted on the healthcare industry effectively adopting the consumer focussed approach. Healthcare services are described as approaching the integration of the consumer oriented model into service delivery using the top-down change management methods. This means that minimal consultation or consideration is given to the cultures, beliefs and values of those groups who are likely to be impacted by such changes. In addition, this approach to reorientation and the difficulties associated with it, are not described as isolated events, but replicated across healthcare settings and services. Despite obvious inadequacies, and minimal indications of
capacity to address underlying problems, maternity and acute care settings continue to refer to consumer participation strategies as influential on healthcare quality outcomes, and endorse the rhetoric that consumer satisfaction is high and healthcare relationships are participative and collaborative.

The second section of the review examined how the philosophy of consumer participation is interpreted or practiced at the individual level of healthcare. The benefits associated with facilitating the consumers’ participation in healthcare are described by national and international experts as fundamentally linked to the quality and safety of healthcare. Despite unanimously supporting the reorientation of healthcare towards focusing on enabling and empowering consumers to participate in their healthcare, the absence of sufficient or reliable evidence acquired through scientific methods of inquiry is identified as a factor limiting the possibility that the experts’ opinion alone would influence the views or behaviours of frontline healthcare providers. It is of interest for this study, that previous inquiries into consumer participation, and its influence or characteristics at the individual level of healthcare, tend to focus on describing organisational features, rather than exploring the behaviour or attitudes of the individual. What is significant in informing this study’s methodology is the literature’s recommendation that if the intention is to meaningfully understand what is essentially a social interaction, then a social science or triangulated approach is a worthwhile strategy.

This section of the literature review broke the practice of consumer participation at the individual level of care into the active components of decision making and information sharing. Descriptors of commonly used approaches to healthcare decision making have been presented under the headings of paternalistic, shared decision making and informed choice approaches. It is argued in the literature that it is not the approach that defines the level of consumer participation or the influence on healthcare outcomes, but rather, it is the respect and trust that each participant has for the other in the decision making process. The review identifies that preparation or recognition of these fundamental concepts is often overlooked.
Consideration of the value that healthcare providers associate with decision making, both at a personal (satisfaction) and professional (identity) level is an area that has not been adequately addressed in the literature. In addition, taking into consideration what the consumer expects, wants or fears from participating in healthcare decision making is an aspect that is largely neglected in existing research.

Healthcare decision making is described as a rationally responsive process, with ambiguous features that do not sit well within the scientific approach to healthcare. The literature suggests approaching this ambiguity by either clarifying the consumer’s expectation and intent to participate in decision making or by maintaining standard practices and reduce variables by not involving the consumer in healthcare decisions. These discussion points support this study’s exploration of individuals’ (consumer and provider) views and behaviours in regard to healthcare decision making.

The purpose of the third section was to explore participation of women within Australian maternity care services and conceptualise the participative elements within the healthcare relationship in the context of ECS.

This section of the literature reveals that although maternity care services are often referred to as pioneers or leaders in adopting a consumer oriented approach to healthcare; it continues to face operational challenges similar to the generic acute public hospital setting. National reviews of maternity care services have questioned the assertion that women centred care prevails beyond the level of policy, and have accused maternity care quality measures as being predominantly defined in terms that met organisational and provider needs or preferences, rather than those of the consumer.

The reliability of the literature review, in relation to exploring consumer participation in designing maternity care for ECS, is limited. Research designs, favoured in the published studies, did not attempt to accurately capture or measure the dynamics of the individual healthcare relationship. The studies tend to focus on collectively addressing the inadequacies of the consumer in
participation efforts, neglecting the provider’s or service’s involvement in the decision making and information sharing components of the healthcare relationship. Due to this focus featuring in a range of studies I questioned whether this is a limitation of study design, or because of limited access to methodologies capable of exploring and measuring subjective interaction. In addition, the likelihood of the studies being led by health researchers raised the question as to whether it was simply more acceptable to question the knowledge and ability of the woman (consumer), rather than critically review their own shortcomings, or their colleagues’ and systems’ capacity to facilitate or engage in healthcare relationships.

The environmental elements and attributes of the individual (professional and social) stood out in the literature as significant factors in creating a setting responsive to activating participation. The maternity care setting is described as equally susceptible to the power imbalances, manipulation and information politics that has traditionally sustained a professional distance between the consumer and healthcare provider. Although these significant features are discussed in the research findings, a propensity to influence consumer participation outcome measures is not directly explored. This limitation reinforces this study’s multi-method approach, which includes an environmental audit and explores communication pathways as a means to capture and understand the factors that influence the involvement of consumers at the individual level of healthcare. In addition, to ensure the meaning of the individual consumer’s survey responses are not lost; I will analysis consumer responses individually, rather than making generalised assertions based on analysis of aggregated data.

The fourth section presented a critique of current methods of monitoring or measuring outcomes of consumer participation. In this review, the concepts of defining outcomes that reflect participation in an individual’s healthcare are complicated by the multidimensional aspects of healthcare interactions. Potential outcome measures include perceived experience (satisfaction survey), observation of the experience (behaviours, verbal, documented) and, the environmental conditions (level of activity, orientation, processes). The
literature suggests a triangulation of perspectives; from the provider, the consumer and an independent observer. To improve the reliability and usefulness of outcome data related to consumer participation and its impact on healthcare it is recommended to gather both qualitative and quantitative descriptors of healthcare interactions.

Schulman’s (1979) and Bastian’s (1996) individual approaches to determining a propensity for a healthcare environment to support an active level of participation by considering the socio-organisational attributes of such environments is useful for this study in that it provides a framework to compare participation data at an individual and organisational level, as well as associating appropriate healthcare outcomes.

The usefulness and credibility of basing assumptions of participation activity on consumer satisfaction responses alone have been critically examined. The literature suggests that consumer satisfaction is not viewed as a stand alone measure of the technical quality of healthcare or considered representative as a measure of the consumer’s participation in their healthcare experience. Satisfaction measures however, are considered to be useful when viewed in the context of consumers’ expectations, in order to determine whether the consumers’ perceived needs are met during their healthcare experiences.

The literature review reinforces the previous section’s suggestion that a broad sweep of the consumer’s experience is required in order to meaningfully understand the intricacies of participation in decision making and information sharing at the individual consumer/provider level of healthcare. Referring to the consumer’s medical record is presented as an opportunity both to understand the context of consumer survey responses and to put context to the medical records content. Determination of participation outcomes can be enhanced if the consumer, provider and organisation are adequately prepared for communicating the consumer’s healthcare experience in terms of physical, cognitive and behavioural measures. This includes flexibility in the organisation of care, responsiveness of healthcare documents and the effectiveness of communication and information sharing strategies. These
recommendations are all considered invaluable in informing this study’s methodology.

The fifth section reviewed the role of the medical record in the healthcare experience. Documentation emerges as a form of social, professional and organisational communication and issues relating to access, legibility, completeness and legal requirements were explored. Healthcare communication is said to be facilitated by the use of documents which: display standardised prompts; reflect the anticipated trajectory of care; include capacity to record variances; and are held or accessible to the consumer and provider alike (such as women held maternity records and clinical pathways). Access to such documents is associated with favourably influencing the technical quality of medical care, consumer satisfaction and attainment of positive health outcomes.

The quality of medical record documentation and the historical use of the contents of the record in validating the medico legal and technical quality of healthcare provision have been explored. Recent national and international studies that use the medical record as the foundation of their assessments of healthcare quality have been critically reviewed for their methodological strengths and weaknesses. In informing this study’s methodology, the literature review indicates that the obstetric medical record is a more complete or accurate record of the consumer’s experience and related decision making, than records of other clinical conditions and healthcare providers. In addition, the reliability of medical record audit data can be favourably influenced by strategies such as: a standardised audit tool; validated coding criteria; and accessing an independent auditor.

Reflecting the recommendations of the previous four sections, a triangulation of methodologies is recommended as the most effective strategy to capture not only the environmental and social constructs of contemporary healthcare, but also the complexity and multiplicity of issues that influence the documentation of healthcare provision. The medical record is described as capable of recreating a documented reality by framing the direct experience of an
individual through the documented perceptions and observations of another individual. In order to holistically capture the reality of the consumer’s experience, it is clear that the views and behaviours of those in direct contact with the consumer, the methods and preferences for communicating healthcare and, the influence of the environment needs to be explored. It is also clear that if these considerations are overlooked in the methodology of this study, than I would be incapable of making sense or would need to make numerous assumptions related to the meaning or significance of the data collected.

**Study Aim & Objectives**

This literature review provides a somewhat descriptive, yet comprehensive, insight into the current body of knowledge relating to consumer participation in Australian healthcare on an organisational and individual level. The review identifies decision making and information sharing as critical attributes associated with fostering a participative relationship between the healthcare provider and the consumer. The review also looks closely at the context of this study's setting. This brought about an acknowledgement that the maternity care setting and the maternity consumer/provider relationship is not unique; in fact they are influenced by the same organisational rhetoric and consumer/provider dissonance that is reported within the generic acute healthcare setting.

The review highlights that healthcare researchers are gradually becoming more aware of the limitations in taking a pure scientific approach to exploring health related interventions, which involve social interactions. Healthcare governing bodies have been described as being genuinely interested in exploring ways of determining healthcare related outcome measures for interventions, including monitoring the adoption of the consumer oriented approach to healthcare. The literature is overwhelmingly in favour of exploring the healthcare relationship using the triangulated or multi-method approach. Using the medical record as a source of healthcare related data for research purposes is validated by the literature. In particular, medical record data is reported to be representative of the consumer’s experience both from
the perspective of the technical quality of healthcare, and for the purposes of validating quality assessment strategies such as consumer and provider questionnaires. This advice, and the gaps and limitations identified in the participation literature, were influential in shaping this study’s aim and objectives.

**Study Aim**

Determining indicators of consumer participation in the planning and delivery of healthcare, in an Australian context, has been stated as the preliminary aim of this study. This study will focus on the surgical procedure, elective caesarean section (ECS), and the examination of the medical record contents as a means to retrospectively extrapolate factors that could be considered representative, or supportive, of consumer participation throughout the healthcare trajectory.

As outlined in Chapter One, there are numerous rhetorics and realities in regard to consumerism and healthcare, and although I commenced this study with an aim, I was conscious of a need to refine the study’s aim by broadening my understanding of the current literature. The preliminary aim is supported by the literature, and the examination of the practice of consumer participation in the planning and delivery of healthcare remains paramount. The literature also supports a need to verify any judgement on the practice of consumer participation, by determining indicators that an individual’s healthcare experience has re-oriented from the traditional asymmetrical patient/doctor relationship, to a joint responsibility or partnership approach between the consumer, the multidisciplinary healthcare team and the healthcare service.

**Study Objectives**

As a result of the literature review findings, the study objectives are confined to:
Observe existing clinical information systems, and detail the
topportunity within, and compliance with, organisational policy and
processes designed to engage, record and evaluate consumer
participation outcomes within the study sites.

Analyse the information sharing and decision making behaviours and
views as reported by the sample of clinicians who were identified as
contributing to the consumers’ healthcare experience through the
study’s medical record audit.

Analyse information sharing and decision making experiences, and
satisfaction with involvement in healthcare, as reported by the sample
of consumers whose medical records fit the study’s inclusion criteria.

Identify and classify the presence or absence of indicators of
partnership in decision making and information sharing documented
within the medical records that fit the study’s inclusion criteria within
each site.

Triangulate the findings from (1), (2) and (3) with the indicators of
participation (4) to firstly, determine whether the medical record
audit verifies the extent to which consumer participation is practiced
within the study sites, and secondly, determine any social,
professional or environmental issues influencing the level of
consumer participation identified.

The following chapter will describe in detail the study’s design and the
triangulation of methods employed to achieve this study’s aim.
Chapter Three

METHODOLOGY

Introduction

The literature indicates that improved health outcomes and a more effective and efficient system of healthcare delivery is more likely when the consumer actively participates at the individual level of healthcare. Factors that are likely to influence the level of consumer involvement in decision making and information sharing include: the individual attributes of both the healthcare consumer and the provider; the dynamics of the healthcare relationship; and the orientation and practices of the healthcare organisation.

The literature also argues that attempts to determine the level of consumer participation at the frontline of healthcare using a single method are likely to be ineffective. Instead, a multifaceted approach is discussed as being a more effective means to capture individual elements of the healthcare relationship.

Given the limitations of previous health research methods, a multi-method, triangulated approach is the most appropriate method(s) for this study. The multi-method approach features the merging of qualitative or social data (such as ethnography, interviews, text analysis) with quantitative data (such as questionnaires and audits). This allows for the variables of an individual’s interactions to be specified, minimising any disadvantages associated with any single method of inquiry (Braithwaite et al. 2002).

As described in the introductory chapter, this study is being completed whilst being a member of a research team which was commissioned to complete a two phased Commonwealth project. Prior to determining the methodology for this study, approval has been sought and obtained from the Commonwealth project’s principal researcher. Hence, this study is a complimentary study, interrelated to Phase Two of the Commonwealth project.
As a member of the Commonwealth project team, I have access to an extensive data base and resources (both human, technical and financial). However, this study remains unique from the Commonwealth project. This study’s data analysis will draw on primary (audit, observation and interview) data that I collect specifically for this study and secondary (questionnaire and audit) data that is collected by the project team. Significantly, the primary and secondary data that informs this study’s data analysis originates from the same sources.

In essence, this study aims to identify consumer participation in practice, examining the medical record, the views and behaviours of clinicians and consumers, and environmental features in order to determine the extent of involvement in decision making and information sharing during the continuum of hospital care for an elective surgical procedure. To explain the study’s methodology, a detailed account of the common components of the study design (i.e. components shared between the Commonwealth project and this study), will be followed by a detailed description of the unique components of the study. Based on the literature review, the study is approached via four Domains (i.e. Environmental, Clinician, Consumer and Medical Record). These Domains were selected because they are representative of the multifaceted aspects of consumer participation at the individual level of healthcare. In addition, the fact that each of the Domains can be linked to the same data source, the medical record will go some way in supporting the reliability of any findings.

**Study Design**

The study design details how aspects such as site and condition selection have been secured, ethics approval obtained and sampling procedures and samples established. In presenting these details, the Commonwealth project’s influence on this study’s design will be evident. The Environmental, Clinician, Consumer and Medical Record Domains will then be individually described. Measuring instruments and methods of data analysis utilised will be the focus
of each Domain’s description. It is these elements that make this study unique to the Commonwealth project.

Site Selection

As mentioned, this study is set in Queensland, complimentary to Phase Two of the Commonwealth project. The health system in Queensland, in comparison to NSW and Victoria, has been credited with demonstrating a strong corporate image, with a more pronounced central control of hospital services at the operational level (Sorensen et al 2001). The attractive features of this health system are that operational control implies relative managerial and policy regulation between hospital sites. These features favour the purposes of this study, as it can be assumed that each site will be functioning within the same regulations in regard to operationalising policy related to the consumer oriented approach to healthcare.

Queensland Health distributed the Commonwealth project’s site selection criterion via the health systems networks. The selection criterion requires the sites to demonstrate a high volume of cases and a self description of the model of clinical care. The Commonwealth team requested (Degeling et al 2000 p. 3) the sites to provide evidence that:

- The level of support that the model of care draws from senior management and the extent to which it, structurally, is integral to both operational management and organisation development
- Service providers are constituted as teams
- Have developed and are implementing an agreed plan about the composition and sequence of tasks to be performed which specifies resource inputs, standard cost and the indicators to assess quality and outcome

1 *evidence of more than 1000 cases of the selected AR-DRG increased suitability of the procedure adopting a standardised approach to organising clinical care

# seeking to exclude settings with a minimum of systematisation as defined from Phase One of the project.
Have access to information systems which are capable of monitoring variation from the production plan, with respect to task composition, sequence, resource usage, quality and outcomes.

Have set in place structures and practices which enable them to evaluate and benchmark their performance over time, and devise agreement about remedial action.

From the four Queensland Health sites that were selected to participate in Phase Two of the Commonwealth project, three sites have been selected for the purposes of this study. One site is not appropriate for this study because it has a large proportion of private healthcare consumers who do not receive antenatal care on-site at the public facility, and are transferred for post-natal care to the private facilities located within the public hospital grounds. This is considered a limitation because the medical records held in the public hospital only detail the consumer's experience in the public service. Hence, due to the complexity this adds to an already complex study, this site is excluded from the sample and the study concentrates on the remaining three public hospital sites.

**Condition Selection**

‘Caesarean Delivery without Complicating Diagnosis’ is the clinical procedure chosen to be explored in the second Phase of the Commonwealth project. The findings from the first Phase of the project indicated that this clinical procedure is more likely to be amenable to work process control structures and processes, in the organisation of clinical care than the two other conditions examined; namely, appendicectomy and transurethral prostectomy (Degeling et al 2000). Phase One of the project demonstrates that ‘AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis’ has two significant features. Firstly, the demographic features of high volume with low length of stay coefficients of variation (Table 3.1) and secondly, a high degree of clinical homogeneity as determined by the distribution of ICD procedure codes the AR-DRG covered (Sorensen et al 2001). A review of the Queensland Health ICD codes related to ‘AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis’ by the Phase Two project team verifies that
the same relatively small number of code combinations is used, and that these combinations (or essentially the same combinations) are a recurrent finding.

Table 3.1 AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis

<table>
<thead>
<tr>
<th>AR-DRG</th>
<th>PDx Rubric</th>
<th>AR-DRG Procedure</th>
<th>Referral Source</th>
<th>Urgent Admission</th>
<th>Service Type</th>
<th>Separation Mode</th>
<th>Payment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>O01D</td>
<td>654</td>
<td>7411</td>
<td>GP</td>
<td>No</td>
<td>Acute</td>
<td>Home</td>
<td>Public</td>
</tr>
</tbody>
</table>

Table 3.1 describes the features of ‘Caesarean Delivery without Complicating Diagnosis’, as predominantly consumers that are referred by their general practitioner (GP), utilise public acute care facilities and are then discharged home.

In reference to this condition’s compatibility with the study’s methodology, ‘Caesarean Delivery without Complicating Diagnosis’ is the most frequently associated with the surgical procedure elective caesarean section (ECS). ECS is described in the literature as featuring: a generically predictive model of care; a capacity for the sharing of information; an acceptance to discussing issues of concern; and an ability to individualise healthcare design (Roach et al 1998; de Costa, C. 1999). ECS consumers, as a study population, are also generalised in the literature as being representative of an age and gender group that is socialised to identifying and expressing their opinion and importantly are not sick consequently, they anticipate a positive outcome to their hospitalisation (Wilson et al 1996; Degeling et al 2000). The features and characteristics listed, suggest that the participation of the healthcare consumer is likely to be supported at the individual level. Significant to this study, features such as these also favourably influence the likelihood of identifying indicators of consumer participation, either at an individual or organisational level of healthcare.

In addition, the appropriateness of selecting ECS for the purposes of this study, is supported by the claim that Queensland healthcare settings function
within a regulatory framework that effects the operation and organisation of clinical care processes across the state, and the ECS consumer’s healthcare experience is assumed to be predictable in a public hospital setting. These features support making data comparisons across each site, as well as on an individual basis, and exploring possible reasons for any differences within the study findings.

**Ethics**

The University of NSW project team obtained ethics approval from Queensland Health and from each site that volunteered to participate in the study. Ethics approval for this study is incorporated into the project team’s ethics submission. Participation in the study is voluntary; participants are informed that they and the healthcare setting will not be identified individually.

**Samples and Sampling Conditions**

Because this study is nestled within the Commonwealth project, the study samples and sampling conditions reflect the second phase of the project’s design. Three sets of samples (i.e. a medical record, a clinician and a consumer sample) are required from each site. This section of the study design, details the sampling conditions required to determine the sample sets. The sampling conditions have been duplicated across the three Queensland Health public hospital sites.

The Medical Record Sample

Phase One of the Commonwealth project identified difficulties in accessing the medical record for research purposes, and a tendency for medical records to be reclaimed by the acute care setting. This resulted in having to withdraw reclaimed records from the study sample producing an incomplete data set. To minimise the impact of such difficulties in Phase Two, the number of medical records requested from each site will be increased from forty to fifty. It is
anticipated that this will assist the project team in reaching their target sample size of forty medical records per clinical setting.

Each site’s medical record department controls access to the records, therefore each medical record manager is requested to make available the medical records coded AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis. To be included in the sample, the medical record has to include admission and discharge dates within the past three months or two medical staff rotations, prior to the research team’s arrival at the site. The three month time frame is set to improve access to medical staff before they progress to their next clinical rotation, and also to increase the reliability of consumers’ recall of their experience. It is anticipated that if more than fifty records fulfil this selection criteria, a random sampling technique will be used to reduce the sample size. In the case of insufficient number of medical records, a population sample within the selection criteria will be necessary. However, the additional sampling techniques have not been required as each site has provided access to between forty-five and fifty records.

Each record provided by the medical record departments bore the code AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis. Prior to finalising the medical record sample and commencing the next stage of sampling, an additional review of the records using the exclusion criteria designed by the Clinical Reference Group from Phase One of the Commonwealth project is completed. The purpose of the Clinical Reference Group exclusion criteria is to further improve the clinical homogeneity or consistency between the record samples. This means excluding records with evidence of:

- placenta praevia
- prior significant medical or obstetrical conditions
- greater than three caesareans
- multiple pregnancies
- significant foetal abnormality
- inter-uterine growth restriction
- unexplained fetal or neonatal death

A project team colleague (a general surgeon) and I are responsible for applying the exclusion criteria to each medical record that meets the initial selection criteria. A medical record is removed from the site’s final sample only after we have both reviewed the record and agreed that it should be excluded.

Because it is significant for subsequent data collection that the medical record be verified as appropriate to be included in the study, the implementation of the exclusion criteria is the first action at each site. As will become apparent, the medical record sample influences both the clinician and consumer samples. As well as being a main domain of this study, the medical record is central to the Commonwealth project design. The additional sweep of the medical records using the exclusion criteria also improves the reliability of any comparisons that will later be made across the clinical settings.

The Clinician Sample

The clinician samples originate from the names of all medical, midwifery and nursing clinicians identified in the final sample of medical records from each of the three sites.

The approach used to define each site’s clinician sample includes: listing all clinicians whose signatures are located in each site’s medical record sample; dividing each site’s signature list into their professional groupings (e.g. midwife/nurse clinician = registered nurse, theatre nurse or certified midwife; medical clinician = surgeon, anaesthetist, RMO, VMO, intern); and, calculating the frequency of each signature, in each professional grouping, for each site. This results in each site having two lists, one identifying midwife/nurses, and the other medical clinicians. The study is designed so that the frequency and distribution of nursing and medical clinicians in each site’s survey sample is an accurate reflection of each site’s clinician signature list. The sampling
objective is to recruit approximately forty clinicians from each site. Referencing the clinician lists (originating from each site’s medical record sample), the project team then invites each clinician to participate in an interview, and complete the self report, closed-ended survey. This continues until the target sample size is met. Each site’s sample is susceptible to the availability of individual clinicians on the designated interview days. Appointment times are coordinated within employed hours, with times ranging between 6.00 am/12 midnight. The final clinician sample is considered a simple random sample.

This sampling procedure reflects the methodology used in Phase One of the project and replicates the method used in Degeling’s 1998 study, ‘Professional Sub-cultures and Hospital Reform’. The sampling is considered reliable, providing that no inferences are drawn as to the incidence of a particular response item in a clinical site or clinical discipline. Using this sampling method, statistical tests and significance levels can be used to describe the strength of a relationship or difference rather than as a basis of an inference to a larger population.

In responding to lessons learnt from previous studies, such as the adverse influence of high staff turnover rates and difficulties accessing or releasing clinicians to participate in research, the research team made site visits prior to recruiting the clinician sample and commencing data collection. This allows potential participants the opportunity to become acquainted with the research project, its purpose and methods, and time to discuss and clarify the meaning of their contribution to the project.

The role that I play in defining the clinician sample includes: compiling the list of clinician signatures identified in the medical record samples; clarifying with the site’s contact the names and disciplines of the clinicians; canvassing clinicians to participate and coordinating appointment times; interviewing clinicians and being available as a resource when clinicians are completing the survey.
The Consumer Sample

The medical record sample is also the source of the consumer sample. The consumer sampling requires each site’s medical record sample to be audited for the consumer’s contact details as outlined in each site’s ethics approval. This requires a letter signed by each site’s executive, to be sent to each consumer with an accompanying project team’s consumer information sheet and written request to participate in the questionnaire. The project team’s covering letter has been approved by each site’s ethics committee and offers the consumer a personal or telephone interview in place of the mailed questionnaire. If personal or telephone interviews are conducted, it must follow the structure of the mailed questionnaire.

The project team are aware that accessing each consumer in the sample is going to be challenging. Lessons learnt from Phase One of the project have prepared the team for barriers such as: the transient nature of residence in contemporary Australian society; the likelihood that details will be recorded incorrectly or illegibly in clinical documents; and, the retrospective nature of the project means that individuals are not informed about the purpose of the study, prior to being invited to participate.

Considerable effort is given to locating the consumer sample by mail. Consumers are provided with a two week window to reply or make contact with the project team, before a second request for participation is made. Where ethics approval allows, non-response consumers are also followed up by telephone.

My role in the consumer sampling procedure includes auditing the medical record for contact details and participating in the distribution and follow-up of mail-out questionnaires. Members of the project team are mindful of the potential for criticism related to the retrospective/mail-out approach to sampling.
Data Collection and Analysis

The literature review informs and supports this study’s aim to use a triangulated multi-method approach to meaningfully understand the multifaceted dimensions of the consumer/provider relationship.

This section details this study’s unique approach by defining the aim, background, sampling, methods and data treatment for each of the study’s four Domains, namely: the Environment; the Clinician; the Consumer; and the Medical Record. The methods described in this segment are independent to the Commonwealth project data analysis; however, occasionally the project team’s data analysis is referenced, in order to compare any relationship between this study’s methods or findings, and those of the Commonwealth project team.

The following section focuses on exploring the study’s four domains and details the instruments and data analysis methods used to determine the level of consumer involvement in healthcare decision making and information sharing.
Domain One – The Environment

Objective: Observe existing clinical information systems, and detail the opportunity within, and compliance with, organisational policy and processes designed to engage, record and evaluate consumer participation outcomes within the study sites.

Figure 3.1 Capturing the Environment

In relation to the study’s aim of determining the level of consumer participation at the individual level of healthcare, Figure 3.1 demonstrates the multi-method approach evident in Domain One. The literature supports examining medical record documentation as a way to meaningfully understand the context of healthcare at an individual level and also because of its capacity to reflect the actions or interventions of clinicians in direct contact with the consumer. However, the literature also indicates that to improve the validity of any data audited from the medical record, the social constructs in which the documentation takes place need to be considered. This domain of the study
examines the influence of indirect aspects of the consumer’s healthcare experience (i.e. environmental issues, professional sub-cultures and organisation of care) that are not able to be captured through a record audit alone, but are considered significant attributes if seeking to meaningfully understand the consumers’ involvement in their healthcare.

In this domain, each site’s capacity to engage, record and evaluate activities relating to consumer participation is examined through observation and evidence gathering. The aim of this approach is to determine if the site’s participative intentions are reflected in the organisation of clinical care, or in the practice or beliefs of frontline healthcare providers. This domain assists in determining the level of participation practiced by determining the extent to which each site’s environment is oriented to the consumer as an active participant in treatment.

The data sources and the methods of data collection and analysis include:

*Walk-through* – Observations / interviews / document audit

*Closed Survey* – Clinicians’ views on consumer participation

*Project Team Data* - Management orientation audit

**The Walk-through**

*Aim:* To explore whether each site within this study demonstrates the socio-organisational attributes required to adopt a consumer oriented approach to healthcare.

*Background:* The literature review introduces the work of Beryl Schulman (1977 Active Patient Orientation framework p.74) and Hilda Bastian (1996 Levels of Consumer Participation framework p.61) as useful in determining whether the socio-organisational attributes of a healthcare service are capable of supporting an active consumer participation level.
It is reported in the literature, that to support an active participation orientation, an organisation must demonstrate evidence of opportunities for: the individual to communicate their attitudes and expectations; collective contribution in determining healthcare management, such as information sharing and decision making partnerships; and, the organisation and clinician to be responsive to the experiences of its users. Evidence of such opportunities being operationalised at the individual level of healthcare are linked with improved consumer health outcome measures such as: favourable treatment outcomes; highly rated quality of healthcare; cognitive outcomes; and behavioural outcomes (Bastian 1996; Schulman 1979; Walsh 1999; Kaplan et al 1989a)

Sample: The sampling techniques used for determining the settings (three self selected Queensland public hospital settings and the clinical procedure elective caesarean section) for this study are detailed in the previous segment of the methodology. A snowball sampling approach is applied to make contact with healthcare providers. Sample size and characteristics are not considered significant (May 1999)

Method: Dave Gustafson (2001) describes the Walk–through as an opportunity for the researcher to become the consumer visiting the healthcare setting. This approach requires the researcher to be the instrument of data collection, one who gathers data by participating in the social world of the consumer’s healthcare experience. This can also be termed participant observation; where the aim is to understand what goes on within a social situation and how the people in this situation act and interpret their environment (May 1999).

Gustafson (2001) outlines the steps in how to conduct a Walk-through in the Quality Improvement resources segment of the Institute for Healthcare Improvement website (www.ihi.org). Gustafson’s (2001) steps have been adapted to meet the objective of this study and include:-

- Choose the patient / procedural pathway
- Become a particular consumer
Let the staff know in advance that you will be doing the walk through (avoids suspicion and increases ownership)

Go through the experience – act as if you have never been there before – follow the signs, ask the clerk – acquire generic and condition specific information pamphlets/service advertising material accessible to consumers

Look around as the consumer might, and ask yourself, “what are they thinking?”

Ask staff about their awareness of strategies or activities designed to engage consumers in participating in service or healthcare planning, how is feedback gained from the consumer? Who is responsible for the distribution, collation and provision of feedback on the consumer survey responses back to the clinical areas?

Ask staff to tell you what changes (other than hiring more / new staff) would make it better for the consumer and what would make it better for the staff?

Sit down and record the staff’s ideas as well as journaling your own ideas, thoughts and feelings.

This method means that frontline clinicians rather than managers are likely to be interviewed. This is not considered a limitation, as the frontline clinician has the greatest access to the consumer; this means that they also have the greatest influence on the individual consumer’s participation. The aim is to explore participation strategies by interviewing frontline clinicians. This provides opportunities to understand the clinicians, by determining their awareness or inclusion in developing consumer participation strategies, and identifying what influences their view of participation strategies may have on the provision of care. The purpose of this line of questioning is to determine whether consumer participation strategies are likely to be influential on daily clinical practices.

Field notes are taken throughout the walkthrough with the aim of capturing the salient features of any observation. Service pamphlets, information hand-outs and clinical documents (e.g. pregnancy health record, progress notes, clinical pathway, patient information sheets and satisfaction surveys) are collected to supplement the interview and observational data. These
documents are considered valuable data sources in their own right, as they hold the potential to inform and organise the decisions and actions which individuals make on a daily and longer-term basis in relation to healthcare (May 1999).

**Data Treatment:** Categories, descriptive of each site’s observed and documented intentions to engage the consumer in participatory and feedback related activities are formed. The categories include evidence of: the mission statement; consumer representation; generic service information documents; condition specific information documents; pre-admission service; provision for recording individualising of care by clinicians; provision for recording individualising of care by consumers; satisfaction surveys/consumer evaluation or feedback methods.

The observations, the staff comments and the content and format of any documents accessed during the *Walk-through*, are then examined in order to understand the influence (if any) that each site’s intentions are likely to have had on actively engaging the consumer in their healthcare experience. In addition, the content and format of the documents are also audited for capacity to: consistently communicate the model or philosophy of healthcare; invite the consumer to participate at the service and individual level of healthcare planning; inform the consumer of what to expect and what is expected; and, provide opportunities for the consumer to comment, seek clarification or access external or complimentary services related to their healthcare experience. These methods of comparison are useful in determining the effectiveness of each site’s participatory and feedback strategies, whilst also identifying discrepancies between the intentions and the implementation of participatory strategies at the frontline of healthcare.

The *Walk-through* data will then be compared and contrasted with Schulman (1977 cited in 1979) and Bastian’s (1996) participation frameworks. This step is taken in order to determine whether the socio-organisational attributes recognised in the frameworks as supportive of an active consumer participation level, actually exist or are likely to be functional in each of the
sites. Each site’s level of consumer participation activity is then explained using Bastian’s (1996) descriptors of participation activities and the corresponding health outcome measures (refer to p.62). This data is useful for future comparative analysis and triangulation with the medical record audit data.

Closed Survey – Clinicians Views on Consumer Participation

**Aim:** To understand whether or not the views and attitudes of the study’s clinician samples are compatible with a consumer oriented approach to healthcare (i.e. shared responsibility in decision making).

**Background:** The literature review suggests that in order to understand, or explain, the level of participation consumers are exposed to throughout their healthcare experience, the researcher must also endeavour to understand the views and attitude of the healthcare professional. Consequently, the concept that the healthcare provider is influenced by the environment in which he/she practices and equally, that the environment is influenced by the provider, suggests a likely pathway of inquiry. However, the literature review identifies that the concept of the provider’s views influencing the level of consumer participation in decision making or information sharing has yet to be explored beyond anecdotal statements or informal observations (Turnbull et al 1999a, Gamble & Creedy 2001, Appleton et al 2000). It is also suggested in the literature, that providers may not be adequately prepared for, or welcoming of, the consumer oriented approach to healthcare. Coulter (1999), argues that clinicians’ attitudes, in particular those of doctors, are likely to be *paternalistic* in preference to *partners* in relation to healthcare decision making and the organisation of clinical care. Appleton et al (2000) claims that healthcare decisions are likely to be associated with the provider’s attitudes towards interventions/treatments rather than the consumer’s preferences, and McMillan (2001) describes clinicians as lacking motivation or being cynical towards the incorporation of participation principles in their practice. One of the aims of this study is to determine the provider’s receptiveness to involving consumers in planning strategies, such as clinical care standards.
Consequently, opportunities are taken to explore the relationships between providers’ views and the level of participation activity, the consumer actually experiences.

Clinical care standards are used as the reference point for this Domain of the study and are defined as a consensus that guides the generic design of clinical healthcare. Clinical care standards are often referenced as being set within a collaborative process, and being unique to the context of each specific healthcare setting. Therefore, in a consumer oriented healthcare model, it is reasonable to assume that consumers are included, in some form, when determining the content of clinical care standards.

Sample: The sampling techniques used to determine each site’s clinician sample, has been detailed in the previous section of this methodology. Survey samples are proportionally representative of the frequency and distribution of nursing and medical clinicians identified in each site’s medical record sample. The target sample size is forty clinicians per site and the literature supports drawing the sample from the medical record audit. Wilson et al (1999) claims that to capture the context (level of participation) of a consumer’s individual experience, sourced from the medical record, the views and behaviours of health providers in direct contact with the consumer are likely to reliably represent the social interactions experienced by that consumer.

Method: Inviting clinicians to complete a survey is considered an acceptable method of gaining data that reflects the clinicians’ perspectives about their actual practices, rather than researcher reported data. The survey tool, ‘A Survey of Clinicians’ Views and Experiences of Clinical Work’ is a twenty page document developed for the purposes of the Commonwealth project team (Appendix A). The survey questions originate from previous work completed by the project director (Degeling et al 1998) and were refined, implemented and evaluated in Phase One of the Commonwealth project (Degeling et al 2000), before being included in Phase Two.
To suit the purposes of the Commonwealth project, the clinician survey is divided into two parts, and aims to enable clinicians to assess the organisation of care for patients, and how this might be improved. Part A is a self assessment of the clinician’s current work practices related to ECS. Part B explores views on clinical practice and the environment in which they practice. The two questions that are useful for this Domain of my study are in Part B of the survey and target clinicians’ views on consumer involvement in setting clinical care standards. A five-point response option scale is provided, from which the clinician is directed to choose the most appropriate response.

The Commonwealth project methodology specifies the conditions in which the survey is to be completed. This means that each clinician (that met the sampling criteria) is contacted individually by the project team. Prior to making arrangements to complete the survey, an explanation of the project and the clinician’s role in the project is provided. A member of the project team meets each participant and personally explains the survey, remaining available as a resource during the completion of the survey. The completed survey is collected and sealed in a plain envelope in the presence of the clinician. The envelopes are then numbered to indicate the site, and returned to the project team for analysis.

Data Treatment: The sampling methodology (p.118) explains that the data collected from this sample is useful if describing the strength of a relationship, or difference; rather than as a basis of an inference to a larger population external to this study. The two questions originate from page eight and nine of the Commonwealth project survey (Appendix A). The first question is located in Part B basis for setting clinical care standard and instructs the clinician sample to consider a string of statements. The statement of interest, asks each clinician to indicate the appropriateness that: ‘clinical care standards should be based on what is acceptable to the patient (consumer)’

A five-point scale listing response options that range from a very appropriate consideration (1) through to a very inappropriate consideration (5) are available to the clinician. Only one response option may be selected. To meet the purposes
of this Domain, the frequency of the response, *very appropriate* or *appropriate consideration* to the statement will be categorised for each discipline, and each site’s data presented.

The second statement relevant to this study is also in Part B setting standards for clinical care and seeks the degree of agreement or disagreement as to whether: ‘patients (consumers) should be involved in setting the clinical care standards’.

The response options range within a five-point scale, from *strongly agree* (1) through to *strongly disagree* (5). The clinicians only select one response. For the purposes of this Domain the responses will be categorised as either in *agreement* (strongly agree or agree responses) or *disagreement* (disagree or strongly disagree responses). The overall agreement and disagreement response frequencies are categorised for each discipline, and presented for each site.

The clinician’s responses to these statements are examined for the purposes of determining whether they view it appropriate to base clinical care standards on what is considered acceptable to the consumer, and view that consumer involvement in setting the clinical care standards is considered acceptable. This provides an insight into how clinicians view consumer involvement. These views are considered to be influential on the context of any decision making interactions that the consumer experiences. The views gained from the clinician samples will be compared for consistency within the sample sets and with the organisation’s intentions to actively engage consumers in healthcare planning (walk-through data). This data will be useful for future comparative analysis and triangulation.

**Project Team Data - Management Orientation Audit**

*Aim:* To compare and verify assumptions/findings that I make about each site’s environmental orientation, with that of the Commonwealth project findings.
**Background:** Phase One of the Commonwealth project identifies that organisational characteristics and management orientation are influential on how each site approaches the organisation and management of their clinical work. Degeling et al (2000) argues that this contextual data is not only useful when interpreting each site’s findings, but critical in explaining the project’s findings in general. As a result, Phase Two of the project places greater emphasis on understanding the organisational characteristics and management orientation of the study sites.

Access to organisational characteristics and management orientation data for the study sites allows this study’s walk-through and clinician survey findings to be compared with the findings of the project team who are exploring the same sites, but using different approaches.

**Sample:** The sampling techniques used for determining the study sites are detailed (p.113) earlier in the methodology.

In determining the characteristics and management orientation of each site, the Phase Two project team canvassed an average of ten participants from each site. A purposive sampling technique determined the interview sample. This technique reflects the fit for purpose approach, where participants are selected according to a known characteristic (i.e. management responsibility). The size of the population is not deemed significant (May 1999) but it is the project team’s intention to attract an interview sample from a broad population. The participants may demonstrate characteristics from the corporate level (e.g. general manager, director of nursing, medical superintendent or chief executive officer), the clinical directorate level (e.g. medical and nursing directors/senior managers or business managers), the clinical setting level (e.g. nurse unit managers, clinical nurse consultants or medical departmental managers) or the administrative staff (e.g. casemix officers, pathway coordinators, quality officers or education officers).

**Method:** Each site’s contact person (e.g. Director of Nursing) is informed by the Phase Two project leader that the research team will be collating data
about the site's organisational characteristics from a number of sources, including semi-structured interviews with corporate and clinical managers. Prior to the project team arriving at the site, the project leader is responsible for explaining the content of the interview schedule (Appendix A) and the characteristics and number of participants required for the interview sample, to each site contact. It is acknowledged that each site’s capacity to provide voluntary participants to complete the interview is dependent on the availability and motivation of individual participants.

The project leader takes responsibility for this level of inquiry and is responsible for: making appointments; completing the interview schedule; making additional notes; collecting significant documents; analysing; and, reporting on organisational characteristic findings.

Data Treatment: In order to meaningfully understand the organisational characteristics and management orientation of each site, the project leader aims to review the data (i.e. interview schedule, interview notes, documents and additional information offered by participants) and categorise the data into themes that represents the influential organisational characteristics identified in Phase One of the project (Sorensen et al 2001). Each site’s organisational characteristics will be tabled into the following categories:-

- The structure of the organisation
- The existence of agreements about expected performance
- The organisation of clinical work
- The structure of clinical work management
- Reporting mechanisms
- The focus of management level meetings

In relation to my study, this data provides a broad descriptive sweep of the environmental and organisational structures which determine how clinical care is provided in the study sites. This data is not intended to be included in the
analysis of my findings. It simply provides an opportunity to verify or determine if any differences present themselves from the way I interpret the organisation and practice of clinical care (and its potential to influence the level of consumer participation at the individual level) compared to the project leader’s findings.
Domain Two – The Clinician

Objective: Analyse the information sharing and decision making behaviours and views as reported by the sample of clinicians who were identified as contributing to the consumers’ healthcare experience through the study’s medical record audit.

In relation to the study’s aim of determining the level of consumer participation at the individual level of healthcare, figure 3.2 demonstrates how the clinician’s self report behaviours and views are used to meet Domain Two’s objective. As stated previously, if the aim is to capture the context of the consumer’s individual experience (multi-dimensional), in order to meaningfully understand the event (one-dimensional medical record content), then the literature recommends using methods that explore the views and behaviours of the healthcare provider in direct contact with the consumer.
Aim: To examine the self report views and behaviours of each site’s clinician sample in relation to the organisation and communication of clinical care and the sharing of information in order to: understand the social orientation in which the medical record is completed, and to facilitate interpretation of the medical record sample’s content.

Background: The literature review identifies that assumptions are being made in the design and discussion of the published consumer participation research. Turnbull et al (1999a), for example, claims that clinicians are fundamentally competent in enabling a participative environment and those clinicians believe that consumers should be involved in their healthcare experience. This study is an opportunity to test this assumption. In this Domain of the study, McMillan’s (2001) description of the contemporary healthcare professional is referred to when determining whether the clinicians are capable of functioning effectively in a consumer oriented healthcare model. McMillan’s (2001) contemporary professional is an individual who is knowledgeable and willing to collaborate and reconceptualise the organisation of their clinical practice into a collaborative model, a professional who views consumers and colleagues as partners in the responsibility of healthcare.

In this Domain, clinicians are asked to consider how they approach, communicate and complete clinical care for the condition ECS. The clinicians’ responses are useful in determining a relationship or contrast in aspects of care such as multidisciplinary commitment to the development, use and evaluation of clinical documents within and across the study sites. The literature favourably associates evidence of a multidisciplinary approach to clinical care with positive health outcomes, in particular, improved healthcare quality and consumer satisfaction. Multidisciplinary commitment to care planning also implies a standardisation or agreement in how the planning, implementing, recording and evaluating healthcare will be approached. Such commitment suggests transparency in the accountability of the individual and the clinical team, which are attributes of clinical environments that are capable of supporting an active level of consumer participation.
Sample: The sampling techniques used to determine each site’s clinician sample have been detailed (p.118). The aim of the sampling is to identify in each site a sample of clinicians who are proportionally representative of the frequency and distribution of nursing and medical signatures that have been identified in the medical record audit. Each site’s clinician sample includes theatre nurses, midwives and doctors, with a target sample size of forty clinicians per site. This sampling method will allow the strength of a relationship or difference in the study’s data to be described, rather than as a basis of an inference to a larger population.

Method: The Commonwealth Project survey, *A Survey of Clinicians’ Views and Experiences of Clinical Work* (Appendix A) has been described in the Environmental Domain (p.127). The content and design of the close-ended clinician survey is the result of an extensive critical review of Phase One of the Commonwealth project. The review included revisiting the literature, and drafting, piloting, reviewing, and testing the revised Phase Two clinician survey. In lessons learnt from Phase One, the project team is aware that, despite every effort being made to reassure clinicians and provide evidence demonstrating the integrity of the survey’s design, clinicians may still view the questionnaire as a method of organisational surveillance. Consequently, although the clinicians may consent and complete the survey, the project team are prepared for medical clinicians in particular, to display limited interest or resistance towards exploring the management of their clinical work (Sorensen et al 2001). This paradox is considered in the discussion of the survey data (Chapter Four).

The tool *A Survey of Clinicians’ Views and Experiences of Clinical Work* (Appendix A) is the only data source for this Domain of the study. The survey data will be organised into four subsets including:

-Clinician Demographics
-Documentation of Healthcare
-Provision of Patient Information
Clinician Demographics

The demographic questions are located at the end of the clinician survey. Completion of these is voluntary and the clinicians are informed that the information they provide will be considered when analysing the survey responses. The clinicians’ capacity to demonstrate McMillan’s (2001) knowledgeable, contemporary healthcare practitioner attributes are approximated by their claim of degree qualification(s) or permanent terms of employment. This approximation is based on the concept that to claim this, the clinicians should (at least) be aware of collaborative or contemporary healthcare models, orientated to the ‘norms’ or standards of their employing organisation and therefore, capable of exhibiting contemporary healthcare practices.

The clinicians’ responses to the Highest Clinical/Academic Qualification and Terms of Employment are therefore of particular interest.

Highest Clinical/Academic Qualification- This question has four response options: postgraduate degree, degree, diploma, and other (please specify). Each clinician is requested to indicate their highest qualification, by ticking the appropriate box. Responses to this question enable an assumption to be made about currency of knowledge and capacity to reflect on contemporary healthcare practices. The reasoning behind this assumption is however limited to the nurse/midwifery samples because over the past twenty years in Australia, this professional group has transitioned from vocational training acknowledged with workplace certificates to enrolment in tertiary institutions acquiring academic degree(s). Such changes at the fundamentals of a profession imply a cultural shift from a traditional prescriptive approach to a contemporary participative ethos is likely. In this context, the nurse/midwife samples who claim degree or higher qualifications are likely to be basing their views on contemporary healthcare theories, with an awareness of collaborative models and the consumer participation philosophy.
As stated, there are limitations in using this demographic variable in regard to medical clinicians because all doctors will report tertiary qualifications. It is also argued in the literature that Australasian medical schools continue to teach traditional institutional practices and are not preparing medical professionals with the attitudes and behaviours required to negotiate or support participation in a contemporary consumer/doctor relationship (ATEAM 2001). Hence, this demographic variable is not useful in approximating the basis of the views held by doctors in the sample on healthcare or their capacity to be knowledgeable of contemporary healthcare practices.

**Terms of Employment**- This question had five response options: full-time staff, part-time staff, casual, contract and other (please specify). Each clinician is requested to indicate their current terms of employment by ticking the appropriate box. The literature reiterates that measuring the concept of individual approaches to work practices through standardised methods, is fraught with environmental and subjective implications. However, by determining the samples terms of employment, I feel confident in assuming that clinicians employed on either a full-time, or part-time basis, are likely to be formally orientated to the site, its policies and procedures. Hence, clinicians who are full-time or part-time employed are likely to demonstrate standardised (similar and familiar) understanding of how their site organises clinical care.

**Demographic Data Treatment**

In order to determine the clinician’s propensity for displaying an awareness or affinity to McMillan’s (2001) contemporary healthcare practices, the responses are categorised into disciplines (e.g. medicine, midwifery and theatre nurses) and sites. The modal frequency and percentage of modal frequency for the demographic variables of highest clinical/academic qualification and the terms of employment are then explored to assist in demonstrating any demographic differences or similarities within and between the clinical disciplines or within and between sites (McKenna 1995; Degeling et al 1998; Degeling et al 2000).
In essence the demographic data is background information, and will assist in understanding the clinician’s responses to the survey questions.

**Documentation of Healthcare**

The survey questions related to the documentation of healthcare are located in Part A of the survey tool (Appendix A) and are grouped under the title 1. *Clinical organisation of the care process*. Part A of the survey elicits the clinicians’ understanding and practices specifically related to the organisation and documentation of clinical care for women admitted for an elective caesarean section. The survey uses closed questions with force response options; therefore clinicians can select only one response.

Part A of the survey includes three questions of relevance to this Domain of the study. Firstly, clinicians are asked to indicate their *awareness* (Yes/No/Don’t Know) of a form that sequences the tasks and activities required to care for ECS consumers. Examples given to assist the clinicians to identify with such forms include: nursing care plans, caremaps, clinical pathways, critical paths or other forms. Secondly, if a clinician claims to be *aware* of a form, the clinician is then asked if they actually *use* the form to organise care and if they *record* on the form when the care path varies from the forms sequences. Clinicians are offered a five point likert scale to choose from; always, frequently, sometimes, seldom, or never.

In my career as a professional, I have noticed that it is commonplace for healthcare sites to print standardised forms, which include clinical care prompts. Adeyi and Morrow (1977) identified that the most consistent and important antecedent of quality maternity care documentation is the use of standardised printed forms, such as care plans or clinical pathways. This may explain the widespread adoption of standardised forms in contemporary Australian healthcare settings.

It is anticipated that by examining the survey responses I will be better able to understand whether: the use of standardised forms is influential on clinicians’ documenting behaviours; clinical disciplines share documenting behaviours;
and, whether clinicians within a specific setting have a shared understanding on the organisation of clinical care. This approach will assist in determining whether the consumer’s clinical path is standardised, and in the event of a variance from this standardised path, if the consumers’ new or altered care path is effectively communicated. These are contributing factors to facilitating active participation at the individual level of healthcare.

Data Treatment - Documentation of Healthcare Survey Responses

Each site’s survey responses are presented to highlight the frequency of medical, midwifery and theatre nurse clinicians who claim to be aware of a form that organises ECS care. For the clinicians who are aware of a form, the frequency of the response options always or frequently for the use or recording of variations from the forms plan of ECS care, are also presented.

Each of the response frequencies are thoroughly examined; firstly as a single clinical discipline and then as a multidiscipline healthcare team. When examining the self report survey responses as a site, Domain One’s data is cross referenced. Each site’s environmental data is referenced for evidence of the accessibility of clinical documents/forms and whether these forms are used in the organisation of ECS clinical care. This approach allows for multi-level comparative analysis of the data (i.e. individual, professional and setting level) for significant response trends. The resultant data is useful for subsequent analysis, particularly in the medical record audit data analysis (Domain Four). In Domain Four, the clinician’s documentation behaviours will assist in meaningfully understanding the absence or presence of documentation in the medical record samples.

Provision of Consumer Information

The survey questions related to the provision of consumer information are also located in part A of the survey tool (Appendix A) and grouped under the title 2. Patient Involvement. The questions enquire about the clinician’s awareness of an information sheet which outlines what women can expect as part of their routine ECS care (Yes/No) and if the clinician actually uses the information
Information sharing is an integral component of consumer participation; therefore, this group of questions elicits the clinicians’ views and behaviours in regard to providing information about ECS care. As an elective procedure, it is expected that each site facilitates information sharing. The literature reports that access to consumer oriented healthcare information is globally acknowledged across consumer groups, conditions and hospitals, to have a relationship on consumers’ determination of satisfaction and evaluation of healthcare quality (Krupat et al 2000). Furthermore, it is frequently cited that in providing standardised information pamphlets, it is likely that the consumer will feel capable of actively participating in decision making processes, in comparison to consumers who have not been exposed to similar information sources (Kaplan, Greenfield, & Ware 1989b; O’Connor et al 1999).

Data Treatment – Provision of Consumer Information

Each site’s responses are presented to highlight the frequency of medical, midwifery and theatre nurse clinicians who claim to be aware of a consumer information sheet related to ECS care. For the clinician who claims to be aware of an information sheet, their tendency to always or frequently use the information sheet when discussing/planning ECS care, are tabled.

Each response frequency is to be thoroughly examined; firstly as a single clinical discipline and then as a multidiscipline healthcare team. When examining the self report responses as a site, Domain One’s data is cross referenced. The environmental data includes what is observed, and evidence of, information sheets being accessible and if clinicians tend to use the sheets when engaging in information sharing related to ECS care. This approach allows for multi-level comparative analysis of the data (i.e. individual, professional and setting level) for significant response trends. The resultant data is useful for subsequent analysis, particularly in the consumer data analysis (Domain Three) where the consumers rate the clinician’s information sharing behaviours.
Communicating Elective Caesarean Section Care

The survey questions relating to the communicating of ECS care are also located in part A of the survey tool (Appendix A) and are grouped under the title 3. Communicating the Care Process. These questions explore clinicians’ views and behaviours in regard to how they determine or know what needs to be done next for a woman receiving ECS care. For the purposes of this Domain of the study, the relevance is whether clinicians use the medical record as a tool to determine a consumer’s progress through the hospital continuum of care. An understanding of how clinicians communicate clinical care within and across professional disciplines is also sought.

In brief, the literature reports that clinicians tend to favour alternative methods of communicating, rather than documenting in the medical record. Clinicians are described as favouring traditional communication practices, such as telephone calls and chance face-to-face meetings, rather than more standardised practices. Parker and Coiera (2000) argue that these traditional communication practices are associated with highly interruptive working environments, and an increased potential for clinical errors. Degeling et al (1998) suggests that midwifery/nursing clinicians are more likely to support codifying and documenting work processes collectively compared to medical clinicians. McKenna (1995) suggests that fragmentation in communication is a reflection of fragmentation in healthcare, and is likely to adversely influence the consumer’s perception of healthcare quality.

The communicating ECS care survey question is useful for Domain Two because it establishes the possibility of congruence in how the clinical disciplines, collectively and individually, know or found out what needs to be done next for a woman receiving ECS care. This question is formatted so that each clinician is faced with a list of communication practices. Next to the communication practice is the numerical scale 1 to 5 which represents the response options of; always (1), frequently (2), sometimes (3), seldom (4), or never (5). Each clinician is instructed to circle the appropriate response on the numerical scale that indicates the extent to which they use the communication
practice when determining ‘what needs to be done next’ for a woman receiving ECS care. The six communication practices examined for the purposes of Domain Two include:

I find out what needs to be done next for an elective caesarean section patient by........

Possession of information that is transmitted verbally in ward rounds or during a shift change

Possession of my occupational protocols / guidelines

Possession of the patient’s medical record

Possession of referring to / knowing the doctors’ individual preferences

Possession of talking with the patient

Possession of a hospital devised clinical pathway

Data Treatment - Communicating ECS Care

Each site’s responses are presented to highlight the frequency of medical, midwifery and theatre nurse clinicians who circle (1) Always or (2) Frequently for each of the six communication practices. When the clinicians rate either always or frequently, this response is taken to be representative of routine practice for that clinician when communicating clinical practice.

Each site’s response frequencies for each communication practice are examined both as a clinical discipline group and then as a multidiscipline healthcare team. This approach allows for comparative analysis on a professional and setting level, for significant response trends across the communication practices. This analysis assists in ascertaining if accessing the medical record is the preferred communication practice, across all disciplines, when determining a consumer’s progress through the hospital continuum of care. The data also identifies the potential for barriers to communicating or co-ordinating ‘what needs to be done next’ between healthcare disciplines. These responses will be useful when exploring Domain Three and Four: that
is, the consumer’s perception of their ECS healthcare experience and the consumer’s experience as determined by examining the data from the medical record.
Domain Three – The Consumer

Objective: Analyse information sharing and decision making experiences, and satisfaction with involvement in healthcare, as reported by the sample of consumers whose medical records fit the study’s inclusion criteria.

Figure 3.3 Consumer Experience of Participation

In relation to the study's overall aim of determining the level of consumer participation at the individual level of healthcare, Figure 3.3 illustrates Domain Three’s objectives. In essence, this Domain seeks to understand the consumers’ interpretation of their participation in their healthcare experience. This involves exploring the individual consumer’s interpretation of information sharing and decision making as well as how the consumer interprets satisfaction with the level of participation experienced throughout the healthcare trajectory.

To overcome what the literature review describes as shortcomings in consumer participation in healthcare research, Domain Three acknowledges participation as a multi-faceted relationship that is influenced by inclusion in decision making and information sharing. In this Domain the consumer is
provided with an opportunity to reflect upon, and rate how they view the participative and collaborative behaviours of the clinicians who provide their healthcare. In addition, a consumer’s expectation of involvement in decision making is compared with the satisfaction they report with that involvement.

Consumers are asked to consider McMillan’s (2001) contemporary clinician attributes. This involves the consumer rating attributes such as clinician information sharing behaviours, shared or inclusive decision making behaviours, and the coordination of care between clinical disciplines. As discussed in Domain Two, this approach is taken in order to determine whether there is an association between consumers perceiving that clinicians exhibit McMillan’s (2001) contemporary attributes, and whether the attributes influenced the consumers’ perception of their ECS experience.

Domain Three also aims to determine if there is an association between how the consumer views the participativeness of their healthcare experience, and what is written in the medical record. The intention is to use the individual consumer’s survey responses as a means to understand the social context of the medical record documentation. As detailed in Domain One, this approach improves the validity of any interpretation that is made of the study’s medical record data.

The sources and methods of data collection and analysis for Domain Three include:

*Domain One data* – Participative and feedback intentions of each site

*Self report closed survey* – Consumer perception of participation

*Medical record audit* – Consumer survey compared with record contents

**Domain One – The Environmental Data**

Prior to exploring the consumers’ views on participation in healthcare, the *walk through* data (Domain One) is revisited. Each site’s observed and documented intentions to engage the consumer in participatory and feedback
related activities are revisited. The methods of documenting, collating and
evaluating the consumer's experience of each site are tabled and the methods
used are examined for the influence they have on the level of active consumer
participation. This is useful for the data triangulation.

**Self report closed survey**

_Aim:_ To collect the retrospective views of the consumer sample as a method
of understanding how the consumer(s) interpret the level of participation
activity, and to determine whether consumers are satisfied with the level of
activity experienced during their pregnancy and/or hospital stay.

_Background:_ The literature review indicates that retrospective satisfaction
surveys are an acceptable method of gaining consumer feedback and measuring
service quality within healthcare and service industries. The self report survey
method is also described as a functional approach to obtaining consumer
feedback from the study’s sample population.

In support of surveying the views of ECS consumers, Degeling et al (2000)
states that in their experience, ECS consumers are representative of an age,
gender and social capacity that are capable of identifying and commenting on
their healthcare experience in relation to their expectations. Wilson et al
(1996) also supports that obstetric consumers are generically more likely to be
able to rationalise and comment on decision making and information sharing
experiences than other consumers of public healthcare services.

The Commonwealth project’s consumer survey (Appendix B) is developed
specifically for the purposes of the project team. The survey reflects the
piloting and developmental phases that were undertaken to ensure its
compatibility with the project’s intended settings and populations. The survey
design centres on consumer satisfaction tools developed specifically for
surgical procedures (the Royal College of Surgeons Surgical audit), consumer
assessment of pathwayed procedures (Intermountain Health Care), or for
general assessment of patient satisfaction with their hospital experience
(Commonwealth-Picker) and with independent advise from the Clinical
Reference Group (Obstetric and Midwifery clinicians). The project team also sought guidance from the Royal Australasian College of Obstetricians and Gynaecologists to assist in defining an acceptable consumer outcome measure; however, an agreed outcome or benchmark could not be decided upon and remains a subject of debate (Sorensen et al 2001).

Based on the rigorous developmental processes and the fact that the consumer survey was piloted in Phase One of the project, the Commonwealth project’s retrospective consumer survey is considered a useful and reasonably reliable data source for the purposes of this study. To ensure the project’s consumer survey meets Domain Three’s purposes, approval was sought and obtained by the project team to include two additional survey questions. These additional questions focus on consumers’ views on feeling involved in decision making throughout the pregnancy, as well as perceived satisfaction with that level of involvement. Exploring the level of involvement that the consumers feel they shared with their healthcare provider during the antenatal period is a significant feature because comprehensive information sharing and decision making is reported to take place during pregnancy, prior to admission. The additional survey questions format and rating scales are complimentary of the project survey and also face the same rigorous review and piloting processes that the Phase Two consumer survey underwent.

Sample: The techniques used to determine each site’s consumer sample, is detailed earlier (p.119) in the methodology. The medical records are the source of the consumer’s postal details, which are required to inform and obtain consent to participate. The availability and accuracy of the consumer’s postal details is a determining factor in the final consumer sample for each site.

Similar to the clinician sampling method, the consumer sampling is also considered reliable, provided that no inferences are drawn regarding the incidence of a particular response item in a consumer grouping. Using this sampling method, statistical tests and significance levels are restricted to describing the strength of a relationship or difference, rather than as a basis of an inference to a larger population.
Method: The Commonwealth Project consumer survey, ‘A Survey of the Recent Hospital Experience of Patients who have had a Caesarean Section’, (Appendix B) is a 12 page document. The survey is designed so that it follows the trajectory of the consumer’s hospital experience, in that it explores the physical surroundings, followed by processes of care, care received and clinician behaviours. Feedback from the Phase One consumer survey identified consumers as having difficulties retrospectively discriminating between specialities in their professional groups, such as discriminating between the behaviours of nurses and midwives individually. Consequently, the consumer survey in Phase Two is modified so that the consumer can rate healthcare provider behaviours within their professional groupings. For example, consumers are asked to reflect collectively rather individually upon, and rate the behaviours of, the Doctors and Nurse/Midwives that care for them during their hospital stay. The survey includes both open and closed questions.

Three clusters of data were drawn from the consumer survey, for the specific purposes of Domain Three:

- Consumer demographic data
- Clinician information sharing and decision making behaviour ratings
- Views on involvement and satisfaction with pregnancy care decisions

Consumer Demographic Data

The first section of the consumer survey is titled About Yourself. This section asks the consumer to identify demographic information including: age group, first or subsequent birth, ethnic origin, postcode, highest educational attainment, total household income, and religion. Each consumer is asked to indicate the most appropriate response by ticking the corresponding box. Completion of the demographic details is voluntary. The consumers are informed, via the survey that any information provided will be considered when analysing the survey responses.
Data Treatment - Consumer Demographic Data

As stated, the consumer sampling method means that inferences to a larger population can not be drawn from a particular response set and treatment of the consumer data is restricted to describing relationships or differences.

The consumer’s demographic data is explored by cross tabulating the data using the SPPS version 10 statistics package. However, despite numerous assumptions being made; for example, being an older mother (35-44 yrs age group), subsequent baby (No – this is not your first baby) and tertiary education as being influential on involvement in decision making and information sharing, the sampling limits any further analysis of the demographic data.

The primary purpose of collecting the demographic data is to cross reference consumer responses with the details recorded in the medical record audit (Appendix E). This data is useful in determining whether the samples of consumers who complete the survey are representative of each site’s medical record sample in respect to demographic features. The demographic data is also useful in making comparisons such as identifying data trends and contrasts across the sites (Appendix G). I was mindful that, considering the small sample size of the study, any further analysis of demographic data would not be meaningful.

Clinician information sharing and decision making behaviour ratings

Section Two of the consumer survey is titled, Rating your Hospital Stay. This section asks consumers to rate a list of features related to their hospital stay. The survey questions are grouped under sub headings and follow the generic caesarean section care continuum from admission through to discharge. The first fifty-one questions ask the consumer to consider six possibilities when responding to the survey statements. The response possibilities include:
1. Excellent (indicates exceptional service that could not be improved)
2. Good
3. Just acceptable
4. Poor
5. Don’t know (indicates that you have no opinion)
6. Not applicable (This option indicates that the aspect being rated does apply to your situation)

The response choices and their corresponding numbers are listed at the beginning of the section and at the top of each relevant page of the survey. The consumer is instructed to choose the most appropriate response and then circle the corresponding number.

To meet Domain Three’s objectives, the consumer survey statements are grouped under the headings of Nursing, Doctors and Coordination of Care and relate to ECS care. Of relevance to this Domain, are the consumer’s views as to what is an appropriate response to these five statements:

- The information provided by the nurses about your condition and care was...
- The degree to which the nurses included you in making decisions about your care was...
- The information provided by the obstetrician(s) about your operation and subsequent care was.
- The degree to which the obstetrician(s) included you in making decisions about your care was...
- The doctors’ and nurses’ coordination with each other about your condition and care was....

Consumer responses to these statements are examined by drawing from the literature (ATEAM 2001; McMillan 2001), which claims that if the consumer considers the nurse or obstetrician to be inclusive in their decision making and information sharing behaviours, then it is likely to favourably influence the participative nature (and the quality) of that consumer’s healthcare experience. The perception of a participative healthcare experience was also likely to influence other outcome measures, such as consumer satisfaction.
Domain Three’s approach provides an opportunity to meaningfully understand the social constructs of healthcare. Examining the consumer’s interpretation of clinician information sharing and decision making behaviour is useful in reconstructing the context of the documentation of the events in the medical record. Comparisons are able to be made between the indicators of consumer participation gained from the medical record and the consumers’ reflections of their healthcare experience.

Examining how consumers view the coordination of care between doctors and nurses also provides an opportunity to investigate McKenna’s (1995) claim that consumers are more likely to report experiencing poor quality of care at the boundary of care between clinical disciplines. The consumer’s views on the coordination of care are also useful when attempting to understand whether the clinician’s self reported communication practices (Domain Two), actually facilitate a coordinated approach to clinical care, which is an attribute that is linked to the participative healthcare environment.

Data Treatment - Clinician information sharing and decision making behaviour ratings

There is no disputing that the consumer’s judgement about the coordination of their healthcare and the behaviours of the clinicians that provide that healthcare is subjective data. It is also acknowledged that any assessment on the quality of healthcare, relative to objective measures or to the care that other consumers receive, can not be generalised. However, consumers’ views are considered to be a valid expression of each consumer’s summation of the social environment in which healthcare is experienced and therefore useful for the purposes of exploring response patterns.

Due to the retrospective nature of the study, the survey questions are grouped as either doctor or nurse focussed. In the first instance, each consumer’s response is collated, tabled and examined individually. Another data table is then created that demonstrates the frequency of the individual response options chosen for the five statements offered. This table also includes a cumulative total of frequencies for each response option. The cumulative total is titled *total behaviour rating* and is calculated by adding the total number of
the response option for each statement within the site. The data is scrutinised at an individual and collective level in an attempt to identify any meaningful trends or relationships that might assist in understanding any interactions that occur during the healthcare experience. This means that consumer ratings of doctors and nurses are examined individually and then compared with the coordination of healthcare ratings. The range of consumer responses and the small response sample limits any further analysis of this data.

**Involvement and Satisfaction with Care Decisions**

The final question bank in Section Two of the consumer survey is titled, *Antenatal Care*. Two statements are listed for the consumer to consider and six response options are available to choose from. The statements are:

- I felt that I was fully involved in decisions made about my care during my pregnancy...
- I was fully satisfied with my involvement in decisions made about my care during my pregnancy....

Consumers are asked to circle the number that best describes their agreement with each statement. The response options include:

1. Strongly Agree,
2. Moderately Agree,
3. Undecided,
4. Moderately Disagree,
5. Mostly Disagree,
6. Not Applicable

The survey’s statements do not seek to identify a specific clinical discipline; they simply seek each consumer’s view on the contribution to decisions about pregnancy care. Feeling involved in decision making is an expected response to these statements, due to the consumer being asked to reflect upon a healthcare experience that is coded, elective surgical procedure without complications; that is, a healthcare trajectory that fulfils a predictive path.
The relevance of these two statements in the consumer survey is to provide an insight into how the consumer interprets their involvement. Domain Three’s data is an opportunity to both determine whether the consumer feels fully involved in decision making and if the level of involvement influences their satisfaction rating. In addition, the consumer’s perspectives are another way to meaningfully understand the medical record’s record of events.

The consumer survey data is useful in meeting the study’s primary aim; that is, to determine indicators that an individual’s healthcare experience has re-oriented from the traditional asymmetrical patient/doctor relationship, to a joint responsibility or partnership approach between the consumer, their multidisciplinary healthcare team and the healthcare service. In collating the consumer’s views, Domain Three’s objective is to compare the consumer data with the evidence of participation audited in the medical record. This comparison will go some way towards determining whether the medical record audit findings are in fact representative of the individual’s participation in her healthcare experience.

In addition, the notion that satisfied consumers are ones who feel that their needs are being met is also explored. A review of the literature shows that despite reporting upon consumer participation at the individual level of healthcare and outcome measures (e.g. satisfaction and/or improved healthcare quality), consumer expectations or perceptions of healthcare needs are unlikely to have been captured or included in the same study’s data sets or data analysis. The literature also suggests that consumers might indicate satisfaction with less than full involvement in healthcare decisions; not an optimal standard of care (Kaplan et al 1989a; NRCCPH 2002). Consequently, it is anticipated that Domain Three’s consumer data will elucidate this area of research.

Data Treatment - Involvement and Satisfaction with Care Decisions

The literature review argues that an aggregated consumer survey response limits the reliability of any resultant consumer satisfaction measures. For this reason, in Domain Three the consumer survey responses are presented and
examined individually. The individual data will be examined for relationships between, feeling involved in maternity care decisions and feeling satisfied with that level of involvement. Furthermore, the frequency of each consumer’s response is collated and presented in sets representative of each site. Each individual response and set of data will be examined for the frequency of the *strongly agreed* response. The literature suggests that when a response of *strongly agree* is chosen from a five-point satisfaction scale, this is a rudimentary indicator of a positive outcome measure or consumer satisfaction (Brown & Lumley 1994; Turnbull et al 1999a). Consumer response trends are compared from within the data sets and across the sites.

**Medical Record Audit**

*Aim:* To determine whether consumers’ view the participativeness of clinicians’ behaviours (e.g. involvement in decision making, information sharing and coordination of care) corresponds with these events in the medical record.

*Background:* It is acknowledged that due to the design of the consumer survey, there is potential for doubt over any generalisations that are made in relation to consumer participation at the individual level. The prediction that the clinicians’ behaviours and practices lack standardisation is a common theme in the literature. This means that the claim by individual consumers that they have experienced a range of behaviours within their healthcare experience is likely to be true, and also likely to complicate attempts to make meaning from an already subjective method of data collection.

In 1989, Cleary claims that by comparing consumers’ survey responses with the contents of their medical record; one source is likely to assist in explaining the other. She reports the emergence of cause/effect associations between the two discrete sources of data. Using this method, Cleary (1989) identifies an association between consumers reporting dissatisfaction and/or low healthcare ratings, with evidence of inadequate or inappropriate processes of care recorded in the medical record. A significant finding of Cleary’s study is that an unfavourable healthcare experience rating by the consumer is not just a
reflection of the technical quality of care; it is more likely to be linked to the consumer being subjected to unpredictable or avoidable circumstances during their healthcare experience. In 1996, Wilson reiterates this point, claiming that by reviewing the consumer’s retrospective satisfaction with the information recorded in the medical record, allows an understanding of the clinical context. Furthermore, it provides an insight into the consumer’s contemporaneous feelings and reactions.

Sample: The approach to defining the medical record samples and then the consumer samples for each site is clearly detailed in the sampling section of the methodology. Based on consumer responses to the earlier survey questions, related to involvement and satisfaction with decision making, a small sub-set is selected from each site for a comparative review with their medical record. Sampling for each site’s sub-set is restricted to the consumers who claim to have had a very positive experience, such as participating in decision making and information sharing, or those who describe themselves as having a distinctly negative or dissatisfying healthcare experience. The data analysis is qualitative, no inferences are intended to the wider population and the sample size is not significant.

Method: This approach requires consumers’ recollections to be framed within the account of healthcare events recorded in their medical record. The aim of this comparative process is to identify if there are situations or circumstances that exist in the medical record, which can account for the consumers’ interpretations or opinion of clinicians’ behaviours. This is an exploratory process, with consumers’ views on the level of involvement guiding the medical record review. A record of the review process was kept in order to capture significant differences or emergent themes between the data sources.

Data Treatment: In the literature review there is a dearth of detail about how to collect or comparatively analyse Domain Three’s consumer and medical record data. The approach taken is experiential. In essence, Domain Four’s data (that tracks each medical record’s indicators of consumer participation in decision making and information sharing through the healthcare trajectory) is revisited
through the *lens* of the consumers’ views (Domain Three data). Assumptions and relationships are sought between what is recorded in the consumer’s medical record with the consumer’s own views of the events. The intention is that this approach will provide unique contextual substance to the content of the medical record and be useful in subsequent triangulation of the data from the four Domains.
Domain Four - The Medical Record

*Study Objective:* Identify and classify the presence or absence of indicators of ‘partnership’ in decision making and information sharing documented within the medical records that fit the study’s inclusion criteria within each site.

Figure 3.4 Medical Record Accounts of Events

This study aims to determine the level of consumer participation at the individual level of healthcare. Figure 3.4 demonstrates how Domain Four’s objectives determine whether the hospital medical record provides a reliable representation of consumer involvement in decision making and information sharing, throughout their trajectory of hospital care for an elective surgical procedure (namely elective caesarean section). It is reiterated throughout this methodology chapter that the medical record is integral to this study; it is an information source and also a feature of each Domain.

In 1985, Wolf argued that the medical record is the link between all factors and persons relating to an individual’s healthcare experience. To determine whether the medical record documentation can actually be considered representative of consumer participation, this Domain is designed so that both
the content and completeness of the record samples can be examined (Figure 3.4).

The primary source of all Domain Four’s data is the medical record. To simplify presentation of the methodology, it is detailed in two parts:

**Medical record content audit**
- Healthcare trajectory
- Consumer participation indicators
- Consumer indicator themes
- Demographic data

**Medical record completeness audit**
- Documentation deficiencies and legibility
- Project team record data

**Medical Record Content Audit**

**Aim:** To systematically examine the contents of each site’s medical record samples for documented indicators of clinician and consumer *partnership* in information sharing, decision making and evaluating healthcare.

**Background:** In 1973 Metsch and Veney reported that by examining the minutes of a healthcare committee meeting, they were able to categorise consumer involvement at the committee or group level by determining the direction/control and interaction/integration of the observations minuted. However, little effort has since been made to either replicate this method, or explore other ways of determining evidence of consumer involvement at the individual level of healthcare. In contrast, considerable research has been completed by reviewing documents, minutes and medical records in an effort to understand the association between the quality of healthcare records and the quality of the healthcare service (Wolf 1985; Wilson et al 1995; AHMAC
1996; Roach et al 1998). Wilson’s (1995) reference to a structured review of the medical record as being the best single source of healthcare information is supported by state and national quality and safety groups’ in their recommendations for improving healthcare quality (AHMAC 1996).

The research described above informs this Domain’s structured review of the medical record. It is the aim of Domain Four to determine the level of participation experienced by each site’s consumer sample through an audit of the medical record’s contents. The hospital medical record is the sole source of data. Each record is audited for documented indicators of the consumer being an active participant in the design and evaluation of their healthcare from the first entry through to the discharge notes.

**Sample:** The study’s medical record sample for each site is determined by the Commonwealth project’s rigorous sampling procedure (p.116). The purpose of applying the project’s exclusion criteria is to promote clinical homogeneity or consistency between the record samples; therefore, minimising variations in the consumer’s healthcare experience and facilitating comparison of data sets.

**Method:** Each site’s medical record sample will be put through the following structured review:

**Categorising the record so it reflects the healthcare trajectory**

Before classifying each of the records into participation indicators, the record’s contents are divided into three broad episodes, representing the continuum of care sequences for an elective caesarean section. These include:

- **Pre-operative care** is documentation from the antenatal period including screening tests, referrals, pre-admission visit, anaesthetic and surgical consults, care plan/pathway and all documentation from admission through to surgery.
Post-operative care is documentation from the return from theatre, postoperative care plan/pathways, progress notes, referral, observation, medication, fluid balance.

Discharge is documentation from the care plan/pathway, progress notes, referral, and discharge summary.

The record audit is structured to facilitate data management, by sequencing potential participation indicators into their corresponding episode of care. Data sequencing allows for participation indicators to be tabled into both frequency and episode of care. This facilitates individual and site comparison, and enables contrasts to be identified within and collectively across the sites in regard to the prevalence or absence of consumer participation indicators.

Identifying Indicators of Consumer Participation

The primary purpose of this approach is to identify indicators of participation from the contents of the medical record samples. To do this, each record’s contents will be carefully scrutinised for observations or actions that indicate the consumer’s inclusion in decision making and information sharing with regards to determining or influencing healthcare needs. This includes, but is not confined by, evidence of:

- documentation by the consumer
- documented responses of direct questions from clinicians
- paraphrasing of requests, concerns, statements made by the consumer
- documentation of discussion topics
- documentation of decision-making processes

With respect to the difficulties identified in previous studies, where contents of the medical record are relied upon as the sole data source, the following issues are taken into consideration: firstly, good documentation practices are far from universal in healthcare (Cowan 2000); and secondly, it is unlikely that
clinical and technical aspects of healthcare are adequately documented (Roach et al. 1998). This suggests that the documentation of decision making and information sharing processes will also be inadequately documented. Despite these considerations, and the methodological limitations of the medical record audit (p. 97), the medical record is still frequently used in contemporary research as a data source and reported to be an effective tool to appraise healthcare quality (Wilson et al. 1995). With these limitations in mind, the study’s design has uniquely compensated for the possibility of absent or inadequate healthcare documentation, with Domain Four’s participation indicator data being triangulated with the data sets collected across all four of the study Domains (Appendix G).

Classifying Indicators of Consumer Participation

A validated coding criterion or professional consensus in order to classify indicators of consumer participation has not been identified in the literature reviewed. Therefore, in order to meet Domain Four’s objective, a data collection guide was designed (Appendix C - Medical Record Participation Indicator Audit Tool). The guide allows for a systematic classification of the record’s contents into three categories; namely, an overt, implied or absent indicator of consumer participation.

In responding to the suggestion that documentation practices are likely to be of variable quality in healthcare, and to ensure that any legible indicator of participation recorded in the medical record is included in the audit data, I intend to be very liberal when deciphering, identifying and classifying the contents from each record. The categorisation of the indicators is explained in more detail below.

Overt Indicator of Consumer Participation

An overt indicator is one where there is obvious documentation in the record. This includes evidence of active discussion in design of care resulting in a collaborative outcome or the evaluation of care provision. An example of an overt indicator is: discussion between the doctor and the consumer on the
ECS surgical technique and the possibility of removing an existing scar, concluding with the doctor suggesting options and then recording the mutual agreement.

Some examples of overt indicators of consumer participation in the record include:

- “Requests indwelling catheter to be inserted after the epidural” (Midwife)
- “For tubal ligation with Filshic clips at caesarean section, previously discussed my preferred technique was modified pomcroy but requests Filshic clips to which I agree” (Doctor)
- “Thirty weeks, mode of delivery discussed, at this stage prefers caesarean section under epidural, will discuss next visit” (Doctor)
- “Requested second bath demonstration, same attended” (Midwife)
- “Patient requesting discharge today, discharge arranged” (Midwife)

Implied Indicator of Consumer Participation

An implied indicator is one where involvement is suggested in the record’s contents. This means that outcomes of the consumer’s involvement are not obvious in the record. An example of an implied indicator includes: ‘will consider options after discussion’, this implies involvement; however, when there is no further reference to discussion prior to the consumer consenting for the surgical procedure, it can only be assumed that discussion took place.

Absence of Consumer Participation

This category is selected when there is an absence of evidence of the consumer’s inclusion in the evaluation or individualizing of clinical outcomes. Absence means that the consumer’s record lacks any evidence of care planning; it even lacks ticks or signatures to indicate that aspects of care are completed. For example, when the consumer’s discharge planning document has the prompt of – baby transport discussed – listed and there is an absence of notation or reference to baby transport being discussed in the medical
record then this is categorised as *absence of consumer participation* in the discharge episode of care.

**Analysis of Indicators of Consumer Participation**

Using the audit tool (Appendix C) as a guide, each record’s documented indicators of consumer participation will be transcribed into the most appropriate category (i.e. overt, implied or absent). At the completion of each site’s record audit, the indicator audit data is entered into the SPPS version 10 statistical package. The SPPS package facilitates a comprehensive exploration of the data, both individually and collectively, in relation to the frequency and percentage of participation indicators, as well as in association with the episode of care. In accordance with the triangulated study design, the *indicator database* for each individual and site will be cross-tabulated with the data collated from the consumer, clinician and environmental Domains (Appendix G).

**Identifying Consumer Participation Indicator Themes**

The literature reviewed for the purposes of this study cautions that a finding of absence is a reasonable possibility when auditing healthcare documents. Consequently, consideration has to be given to the approach if all the indicators are absent in the medical record samples.

Methods of data collection and analysis that emerged through the process of planning this study, included taking the time to explore in detail the themes or issues that surround the *presence* of participation indicators; that is, *implied* or *overt* documentation. Therefore, to extract meaning from the indicator audit data, examination of the aspects of healthcare that tend to indicate a collaborative or participative healthcare experience is an important step. To collect this data, a second review of Domain Four’s *overt* and *implied* sequences of documentation is completed. To assist in examining the aspects of care related or surrounding the presence of participation indicators, the *overt* and *implied* indicators are grouped into their common themes, directly related to information sharing and healthcare decision making. The themes are then
tabled and the frequency of the themes are examined both on an individual basis, within and across the study sites, for commonality in documentation of participation indicators.

A significant feature of the data analysis is looking for commonality in the aspects of healthcare (themes) in which clinicians tend to document participative interaction with the consumer. Such findings would encourage further conjecture as to how clinicians discriminate between what they report in the record and what they are responsible to report upon. Identifying themes will also be useful in the data triangulation and in identifying areas for further research.

**Collecting Medical Record Demographic Data**

Demographic variables are collected in Domain Four for the purposes of providing background information and consideration of factors that might influence various aspects of consumer participation within the overall study. The demographic information extracted from each site’s sample of medical records includes: maternal age, number of previous birth experiences, financial category for admission to hospital for this procedure and, clinical indicator for the procedure.

**Demographic Variables**

*Maternal Age:* The individual consumer’s date of birth and age at the time of admission is collected from the record’s admission documentation. Each site’s medical record sample is then grouped into the three categories that reflect the response options offered in the consumer survey. The age category ranges includes 18 – 24, 25-34 and 35-44 years.

*Birth Experience:* Previous birth experience is extracted by reviewing each consumer’s previous pregnancies or ‘obstetric history’ as documented in the record. This variable is recorded as the number of previous live births; abortions or miscarriages are not included. The medical record sampling criteria (p.117) has already ensured that women who may have experienced a
stillbirth are excluded from this study. The range of birth experiences are
categorised simply as first, second, third and so on. The reliability of the
‘obstetric history’ data is confirmed by reviewing the medical record’s
contents for consistency, as the documentation of birth experiences is
dependent on the woman disclosing the information to her care provider.

Financial Category: This data is extracted from the HOSPAS Financial
classification code system that is identified as the standard coding system
across the sites. The admissions clerk is responsible for entering the code
when the consumer completes the admission documentation and elects to be
either private–chargeable or non-chargeable. It is the intention to compare and
contrast the records of private and public healthcare consumers. However, as
this study is completed in public hospital sites, there are obvious limitations in
attaining a sample that can be considered representative of the private
healthcare consumer’s experience.

Clinical Indicator: It was identified in the initial planning for this study, that
each of the sites has provision in its record for documenting the designated
clinical indicator for the procedure. This finding supports the assumption that
coding records using the clinical indicator data is common practice across the
sites. It was the initial intention to investigate how the reported indicators
compare with the standardised Obstetrics and Gynaecology Indicator Set
Version 2. However, when seeking to identify benchmarks for comparison, it
was noted that national consensus for indicators for elective caesarean section
did not exist. The lack of consensus is frustrating for this study and is also
reported to be a source of frustration nationally. For example, the Senate
(1999) report claims disappointment at the inability to determine the origin(s)
of the significant variations of rates across the nation.

Data Treatment – Demographic Variables

The demographic variables collected from the record samples are entered into
the SPPS version 10 statistical package. As stated earlier, the study’s small
sample size limits any meaningful statistical analysis of demographic data.
However, as detailed in Domain Three, the demographic data will be useful in determining the representativeness of the consumer survey sample (Appendix E) and allows for comparison of demographic trends across the three sites in the data triangulation (Appendix G).
Medical Record Completeness Audit

Aim: To explore validity and reliability issues related to the medical record participation indicator data by examining the completeness (lack of deficiencies) of the medical record and comparing this assessment with findings made by another researcher.

Background: Throughout this study, I have referred to the medical record as the most complete data source in relation to the consumer’s healthcare experience. However, this statement is contradicted by the frequently reported criticism of the medical record being incomplete. This is primarily due to poor documenting behaviours and issues related to the organisation or coordination of healthcare. To minimise the implications of this paradox on the credibility of Domains Four's data, the literature supports taking steps to ensure that any interpretation made in relation to the absence of consumer participation indicators in the record, is in fact indicative of an absence of participation and not just a deficiency in the recording of clinical events (Wilson et al 1995; Adeyi and Morrow 1997; Cowan 2000).

To determine the completeness of the record samples, both local and international literature supports the use of structured audit tools, such as that designed for the purposes of the Quality Health Care Study (Wilson et al 1995). Wilson’s audit tool maps the consumer’s trajectory using the pre-operative, post-operative and discharge documents. Numerous studies have referenced Wilson's audit tool and the tool's validated coding criterion features in the Commonwealth project's medical record audit tool (Appendix D).

As I am both the auditor and data collector for Domain Four’s consumer participation indicator audit, it would be beneficial if I could demonstrate inter-rater reliability of the audit data. Inter-rater reliability (i.e. applying an independent assessment to an identical data source) is described by Aaronson & Burman (1994) as a method of rationalising the reliability of medical record data collected for research purposes. Consequently, there are two intentions...
for Domain Four. The need to rationalise my consumer participation indicator audit data by auditing the same medical record samples for completeness beyond consumer participation indicators. Furthermore, comparison of the record audit data, with data collected by the Commonwealth project team (e.g. where another auditor, in isolation to my audit, collects data on the completeness of the same medical record samples; Appendix F) is of benefit.

**Sample:** As detailed (p.116) Domain Four's medical record samples fulfil the Commonwealth project's rigorous sampling procedures. The purpose of applying the same exclusion criteria is to promote clinical homogeneity or consistency between the record samples; therefore, minimising variations in the consumer's healthcare experience and facilitating comparison of the data sets.

**Methods:** This component of Domain Four features an examination of each site's medical record sample for completeness through a validated coding criterion and then comparing my assessment of overall completeness with that of another researcher who has examined the same medical record samples. The structured review processes used are outlined below:

**Medical Record Documentation Deficiency and Legibility Audit Tool**

To provide data about the completeness (lack of deficiencies) of the documentation within the medical record, the methodology includes using the documentation audit tool designed for Phase Two of the Commonwealth project (Appendix D). The audit tool (similar to the participation indicator audit, Appendix C) follows the healthcare trajectory via pre-operative, post-operative and discharge documentation. The Phase Two audit tool is an adaptation of the methodology and criteria used in the Quality Health Care Study (Wilson et al 1995) which is recognised as a valid instrument by the ACSQHC (2000).

In preparation for the role of medical record auditor for the Commonwealth project, I attended a three day training workshop at the Quality Assurance
Department, Royal North Shore (QaRNS) where I was assessed for competency in applying the QaRNS methodology on a sample of elective caesarean section medical records. In brief, QaRNS is a consumer centred quality improvement program that employs a medical record review methodology to identify events, with or without adverse outcomes, which can be attributed to healthcare management (Wilson et al 1995).

The QaRNS methodology has twenty-four general screening criteria, that when applied to a medical record are considered a reliable indicator, or trigger, of an increased likelihood of an adverse event occurring, which can be directly related to the consumer’s healthcare experience (QaRNS Programme Review Manual, 2000). For the purposes of this Domain, I am able to extrapolate from the Commonwealth project’s audit tool (Appendix D) data relevant to two of the twenty-four general screening QaRNS criteria; that is, documentation deficiency by medical (QaRNS criterion number 20) and nursing staff (QaRNS criterion number 21).

Description of the QaRNS medical and nursing documentation deficiency screening criteria includes documentation that is:

- illegal, illegible or inappropriate
- missing, i.e. entries, date, time or designation
- recorded on non identified sheets
- limited or no documentation relating to a clinically significant event
- no nursing documentation for a twenty-four hour period
- absence of medical documentation for greater than four days on general wards and greater than one day in high dependency areas.

Prior to applying the QaRNS screening criteria to the study’s medical record samples, it is necessary to identify each site’s principal system of documenting healthcare. Based on my professional experience and the QaRNS training program, I am aware that in Australia there are two methods commonly used
to record healthcare. Firstly, the progress notes, which allows for unstructured handwriting by those involved either directly or indirectly in the consumer’s healthcare experience. Secondly, the clinical pathway document, which acknowledges completion of standardised, sequenced, defined care processes with a signature notation by those who provide the healthcare. The clinical pathway document also allows for variations in healthcare to be documented using an open format, which may or may not be coded. These two forms of documentation are the focus of this audit.

For the purpose of this Domain, the aim is to determine the overall completeness of each record’s documentation. The QaRNS methodology defines incomplete documentation of care as an absence of a signature(s) on the pathway document(s) or the completion of assessment form(s), progress notes or documents such as anaesthetic reports. Absent documentation is defined as; the absence of the evidence of notation of a clinically significant event (eg consent), or the absence of notation within the time frames for clinicians, as determined by the QaRNS criteria number 20 and 21. Legibility of the documentation, including the clinician’s signature and designation, are also assessed.

Data Treatment – Documentation Deficiency and Legibility

The audit data is categorised to reflect the consumer’s progress via the pre-admission to discharge documentation. Each site’s deficiency and legibility audit data is collated, summarised and tabled, demonstrating the incidence of completeness of documentation using the medical and nursing staff QaRNS criterion (Appendix F). The audit data is entered into the SPSS version 10 statistics package to facilitate cross-tabulation with the participation indicator data. The documentation deficiency and legibility audit data provides an opportunity to scrutinise any documentation trends within the sites and explore generic documenting behaviours of healthcare providers within individual sites and discipline groupings. This data is included in the triangulation of the study findings (Appendix G).
Comparison with Project Team Record Data

In being a member of the Commonwealth project team, I have access to an audit of the study’s medical record samples by another auditor, who is experienced in reviewing and coding Queensland Health medical records. The professional clinical coder’s role in the project is to determine conformity, consistency and presence of both the documentation and coding across the Queensland sites. The professional clinical coder is responsible for advising the project team as to whether the standards of documentation varied across the sites, confirming whether the record’s structure and completion is consistent, or if there are variations within the sites (Sorensen et al 2001). Confirmation of consistency will support the reliability of the study’s record audit methodology, supporting comparison of the data across the sites. This will assist in containing criticism that the study findings are only the result of differences in the standard of documentation across the sites.

Data Treatment – Project team data

The Commonwealth project’s professional clinical coder’s data is accessed and reconfigured so that it can be tabled in a similar format to my completeness data sets (Appendix F). Inter-rater reliability is determined on the basis of comparing the completeness and legibility data collated by the project team’s coder and myself, for each site’s record sample. In clearly demonstrating consistencies and differences between the data collated and analysed by two researchers, who applied independent assessment to an identical data source, adds to the credibility of Domain Four’s methodology and resultant data discussions.
Methodology Summary - Opportunities and Limitations

In Chapter One, this study’s preliminary aim is framed as an opportunity to determine indicators of consumer participation in the planning and delivery of healthcare in an Australian context. My inclusion in the Commonwealth project team, gave me an opportunity to design and enact a study that focuses on identifying consumer participation in practice, within the context of the healthcare consumer’s experience of ECS in three Queensland Health public hospitals.

Chapter Two highlights the dearth of literature that examines the practice of consumer participation in the planning and delivery of healthcare at an individual level. The literature supports the usefulness of determining indicators that an individual’s healthcare experience has re-oriented from the traditional asymmetrical patient/doctor relationship, to a joint responsibility or partnership between the consumer, the multidisciplinary healthcare team and the healthcare service.

A multi-method approach featuring data triangulation is presented in the literature as the most appropriate methodology for the study’s aims. Triangulation, in the context of this study’s focus, allows for opportunities for comparison and contrasting of the multifaceted factors (Environment, Clinician, Consumer, and Medical Record) that are considered influential on the level of participation that the individual healthcare consumer experiences. Most importantly, triangulation improves the opportunity to identify consumer participation in practice.

Chapter Three, outlines the data collation methodology for the four Domains. This includes coding, entering and exploring the data using tools that are designed specifically for this study (Appendix C), tools that have been sourced from the Commonwealth project and refined for this study (Appendix A,B,D) and the SPPS version 10 statistics package. Significantly, each of the data sets are to be examined independently before being collated, cross-tabulated and contrasted on a generic level. This approach addresses the limitations
identified in the literature review, where meaningful interpretation of the findings from other studies of consumer participation is complicated by the tendency to aggregate data. Aggregation of the consumer data effectively marginalizes any individual context that the data represents, and hence is avoided in this study.

This study therefore, provides an opportunity to demonstrate the value of the individual analysis of data sets. For example, the uniqueness of each individual’s healthcare experience is maintained by examining each medical record on its own merits for indicators of consumer participation. In addition, consumers’ responses are examined exclusively and then within the context of the medical record. This is followed by the data triangulation, where the consumer sample’s data is compared with the incidence of participation indicators, and each site’s clinical, environmental and organisational data (Appendix G) is cross tabulated.

The literature highlights a number of risks associated with using the medical record as the source of consumer participation indicators. The medical record itself, regardless of issues related to consumer participation, has a reputation for impacting on the reliability and the validity of research findings. However, the medical record continues as the primary source of evidence that clinicians do involve women in designing and planning their healthcare experience. In recognition of the international and national publications that link maternity models of healthcare with opportunities for information sharing and partnership in decision making, it is evident that in the context of this study the medical record is likely to be a dependable source of consumer participation data.

Factors that have been reported in the literature as impacting on the reliability and validity of data extracted using a medical record audit methodology includes: training and preparation of the coder; specific criteria for coding; open ended format for recording; coding variables; independent interpretation of data by coders; and, clinical expertise. In Chapter Three, each of these considerations has been deliberated in the study design so as to minimise any
criticism regarding the credibility of the study’s methods and resultant data. For example, initiatives taken to maximise the credibility of the study’s data include: selecting a record sample which conforms to a pre-determined clinical homogeneity exclusion criteria; the time frame is set so as to increase patient recall and to improve access to the clinician samples; the researcher has over twenty years healthcare experience in the clinical setting; the project team’s professional coder is recognised as an expert in assessing the quality of documentation; and capturing the social context of the quantitative medical record data is explored through seeking out alternate qualitative data sources such as observation, interviews and questionnaires.

Limitations that have been difficult to circumvent are: conducting a pilot study; locating a validated coding criterion in the literature; and, professional consensus as to defining an elective caesarean section consumer outcome measure. Therefore, this study’s participation indicator coding criterion draws upon the literature related to decision making, communication and information sharing within the healthcare context. The classification and coding of the participation indicators is essentially experiential. The code criterion will be evaluated to determine its appropriateness and reliability in the context of this study.

In regard to the study’s population, a number of issues have been taken into consideration in the study design. As a member of a larger project team, there are some issues that are beyond my personal influence; however, the impact that the sampling design is likely to have on this study has been thoroughly investigated. National and international studies set within maternity healthcare frameworks have not identified an adversity to samples that demonstrate individual characteristics, such as demographic, economic and cultural attributes. As reiterated throughout this chapter the inferences that emerge from this study’s data are useful for describing specific relationships or differences, rather than inferences to a larger population. However, as this study is associated with a larger multi-site, multi-state study, there is the potential to extrapolate whether the data relationships have global significance.
The following chapter presents the study’s findings. The sampling outcomes are presented, followed by each Domain’s data sets being presented and summarised.
Study Findings

Introduction

This study aims to identify the practice of consumer participation in decision making and information sharing, during the continuum of hospital care, for an elective surgical procedure. The rationale for the study design and the selection of the condition, sites and samples, has been detailed in Chapter Three. This chapter commences by detailing the study's sampling outcomes, followed by the presentation of the study's findings within the four Domains. Discussion of the study’s significant findings and data trends will follow this chapter.

Sampling Outcomes for the Three Sites

The previous chapter explains in detail the methodological links between the Commonwealth project and this study. The three public hospital sites and the surgical condition, AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis known as elective caesarean section (ECS), are two aspects of the study design that are directly influenced by the Commonwealth project. This section presents the outcomes of applying the Commonwealth project’s sampling criteria to each site’s medical record, clinician and consumer populations. For clarity in the presentation of the findings the sites will be identified as either site A, B or C.

Medical Record Sample

Each site’s medical record sample is determined by the ICD procedural code AR–DRG V4.1 O01D Caesarean Delivery without Complicating Diagnosis and the application of the Commonwealth project’s exclusion criteria. Thirty-nine to forty-one medical records per site met the sampling criteria. Table 4.1
demonstrates the number of medical records in each site’s sample and are the source of each site’s data set.

Table 4.1 Number of medical records that fulfilled sampling criteria for each site

<table>
<thead>
<tr>
<th>Site</th>
<th>Final Medical Record Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>41</td>
</tr>
<tr>
<td>B</td>
<td>39</td>
</tr>
<tr>
<td>C</td>
<td>39</td>
</tr>
</tbody>
</table>

**Clinician Sample**

Each site’s sample of clinicians is generated from the contents of the medical record samples and is determined by the frequency and distribution of clinician signatures in each medical record in the sample(s). With the objective of securing a sample of forty clinicians each site’s sampling frame is proportionally representative of the discipline signatures identified in the record samples. Table 4.2 illustrates the clinician sampling frame and the clinician sample for each site.

Table 4.2 Clinician Sampling Frame and Clinician Samples

<table>
<thead>
<tr>
<th>Site</th>
<th>n = record sample</th>
<th>Sampling Frame: Frequency and Distribution of Clinician Signatures in each Site’s Record Sample</th>
<th>Clinician Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Total clinician signatures</td>
<td>Midwife / nurse signatures</td>
</tr>
<tr>
<td>Site A</td>
<td>n = 41</td>
<td>311</td>
<td>219 (70%)</td>
</tr>
<tr>
<td>Site B</td>
<td>n = 39</td>
<td>178</td>
<td>124 (70%)</td>
</tr>
<tr>
<td>Site C</td>
<td>n = 39</td>
<td>192</td>
<td>146 (76%)</td>
</tr>
</tbody>
</table>

Table 4.2 shows the frequency and distribution of clinician signatures in each of the site’s record samples. For example, the sampling frame from Site A’s forty-one records totals 311 clinician signatures. The 311 clinicians are
identified as being either a midwife/nurse signature (219) or a doctor signature (92). The percentages listed in Table 4.2 are included to demonstrate that each site’s clinician sample is proportionate to the frequency and distribution of clinician signatures in the site’s sampling frame. For example in Site A, midwife/nurse signatures are representative of 70% (219/311 signatures) of the site’s sampling frame; consequently, Site A’s clinician sample reflects the sampling frame with 75% (24/32 of the sample) being midwife/nurse clinicians. The clinician sampling methodology is replicated across the sites, with each site’s clinician sample being more or less representative of the site’s sampling frame sourced from the record samples. Each sample size equates to 80%–95% of the target sample.

Consumer Sample

Each site’s sample of consumers is generated from the contents of the medical record samples. However, due to the retrospective nature of the study, the use of the medical record to source the consumer sample has limitations. Factors such as the tendency for consumers to be transient in their place of residence and that contact details are sometimes either recorded incorrectly or incomplete, means that some consumers are unable to be located by the postal method. Consequently, it has not been possible to provide every consumer identified in the medical record sample the opportunity to participate in the study.

Table 4.3- Outcomes of Consumer Survey Sampling Method

<table>
<thead>
<tr>
<th>Sites</th>
<th>Consumers whose medical records lack adequate postal contact details</th>
<th>Sites n=medical record sample minus consumers whose records postal details were inadequate</th>
<th>Returned surveys that consent to participate</th>
<th>Returned surveys that decline to Participate</th>
<th>No response or returned survey after second mail out</th>
<th>Survey response rate in relation to the number of consumers whose records included postal details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site A</td>
<td>8 (19%)</td>
<td>n= 33</td>
<td>21</td>
<td>3</td>
<td>9</td>
<td>24/33 (73%)</td>
</tr>
<tr>
<td>N=41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site B</td>
<td>12 (31%)</td>
<td>n=27</td>
<td>21</td>
<td>4</td>
<td>2</td>
<td>25/27 (92%)</td>
</tr>
<tr>
<td>N=39</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site C</td>
<td>3 (8%)</td>
<td>n=36</td>
<td>23</td>
<td>2</td>
<td>11</td>
<td>25/36 (69%)</td>
</tr>
<tr>
<td>N=39</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.3 demonstrates the outcomes of the study’s consumer sampling process. For example, Site A’s consumer sample, sourced from the site’s sample of forty-one medical records, shows that eight (19%) of Site A’s records have inadequate consumer postal details, meaning that only thirty-three of the consumers could be offered the opportunity to participate in the study via the postal method. From the thirty-three consumers who had the information/survey posted, twenty-one consumers gave consent to participate in the study, three consumers declined to participate and despite a second mail-out nine consumers did not respond. The final column in Table 4.3 indicates that from the thirty-three consumers who have been posted a survey, twenty-four consumers either gave consent or declined to participate, giving a response rate of 73%. This approach to defining the study’s consumer sample is replicated in Site’s B and C. Table 4.3 shows that when excluding the consumers whose postal details are inadequately recorded in the medical record (8% - 31%), the consumer survey return rate ranges from 69% - 92%.

Summary of Sampling Outcomes

Figure 4.1 demonstrates the usefulness of the Commonwealth project’s sampling methods in providing access to the environmental, clinician, consumer and medical record samples required from each site within this study. From the three Queensland Health public hospitals, known as Site A, B and C, 199 medical records fulfil the study’s inclusion criteria. A total of 104 clinicians and 96 consumers make the study’s sample complete.

The medical record is shown to be an adequate source for determining the clinician samples; however, the record samples are an inadequate source of consumer postal details (for the purpose of the study’s retrospective survey). The lack of adequate postal details recorded in the medical record is a limitation of the study’s methodology, followed by an inability to track the reasons why some consumers have not responded to two mail-outs of the survey package. It is not known whether the consumers had moved from the postal address identified in their medical record, the postal details are incorrect or survey packages had ‘got lost’ in the postal service; consequently,
this method of offering consumers the opportunity to participate in research should be reconsidered for future studies.

Figure 4.1 Summary of Study Sampling

Four Domains of Participation Data

As detailed in Chapter Three, this study is designed to determine the extent of consumer involvement in decision making and information sharing, during the continuum of hospital care, for an elective surgical procedure. To meet the study’s objectives (p.109), four spheres of influence or ‘Domains’ of participation have emerged; namely, the environment, clinician, consumer, and medical record.

This chapter presents each site’s findings in their Domain. The findings are presented in this way in order to allow each Domain to be evaluated for its potential to directly or indirectly influence the frequency, location and intent of the consumer participation indicators in the medical record samples. Discussion of the triangulation of the findings from the four domains of participation follows in Chapter Five.
Domain One – The Environment

In the first Domain, the intention is to determine a site’s environmental capacity to actively engage consumers in their healthcare. In this Domain the participative intentions of each site will be examined together with observations or evidence of such intentions being practised. The approaches used in this Domain are designed to assist in meaningfully understanding each organisation’s participation orientation.

The findings are presented under three sub-headings: participatory and feedback strategies; clinician survey findings; and, independent management orientation. A summary of the key findings concludes the presentation of Domain One – The Environment.

Participatory and Feedback Strategies

In this section, each site’s intentions to incorporate participatory and feedback strategies within their service planning is presented. To do this, evidence of each site’s capacity to support a consistent standard of care, facilitate coordination and foster communication has been sought and examined. The literature review links these environmental attributes to an organisation’s capacity to actively engage consumers in healthcare. Bastian’s (1996) consumer participation framework (detailed in the literature review p.62) is the structure used to describe the level of consumer participation activity present at each site.

The following tables describe the evidence of participatory and feedback intentions and the application of these intentions for each site. The analysis of Site A’s findings is described in detail first. The data from Sites B and C underwent identical analysis. To prevent repetition, a brief summary will follow each site’s table of findings describing the level of participation activity by applying Bastian’s consumer participation framework (1996). This section concludes with a summary of key findings.
Site A’s Participatory and Feedback Findings

In completing the walk-through, there is evidence of participatory or feedback strategies in Site A’s clinical environment. The evidence collated is tabled below (table 4.4). The *Italic Font used in Tables 4.4- 4.6, denotes my comments (based on observation, interview and document audits) on how the participative intentions are applied in the site.

Table 4.4 Site A’s Environmental Attributes and Participative Intentions

| Mission statement | ‘To excel as an organisation which provides leadership in the provision of health services.’
| Stated belief that patients have the right to participate in the planning of their own healthcare; invited comments or suggestions about the ways in which services could be improved.
| Core Values – care and compassion; dignity, respect and trust; teamwork and partnership; honesty, integrity and openness; best use of resources; continuous learning and improvement.
| Consumer Rep | Yes
| Two consumer reps on health council, consumer representative on maternity service planning *Consumer representative was a pregnant healthcare worker.
| Generic Service Info | Yes
| *Does not identify consumer representative service or how to access internal/external feedback mechanism for consumers
| Condition Specific Info | Yes
| Patient Pathway for caesarean section delivery
| Pre-Admission Service | Yes
| Multidisciplinary
| Provision for record individualising care by clinicians | Yes
| Pregnancy Health Record; Multidisciplinary Clinical Pathway – Caesarean Section - Special needs / variance; Progress Notes
| Provision for record individualising care by consumers | Yes
| *Provision on back page of eight page pregnancy health record document for women to record questions and their pregnancy, clinicians stated this page is seldom referred to.
| Satisfaction surveys/ Patient evaluations | Yes
| Satisfaction survey distributed with postnatal package covers from outpatient to discharge. Likert satisfaction scale and open questions on service improvement. Pregnancy health record evaluation and working party reviewing findings. *Unsystematic process, limited feedback or impact from consumer survey, clinicians seek verbal consumer feedback

Table 4.4 shows that Site A’s intention is to facilitate an environment supportive of an active consumer orientation. Despite this initial
generalisation of the data, my attempt to validate the application of the intended participatory strategies reveals several discrepancies. In comparing Site A’s participative intentions with Bastian’s (1996) consumer participation activity framework; Site A’s intention to enable participation is tokenistic and the participation level ranges between Restricted Scope and Open Involvement. This means that it is likely that Site A’s participation strategies reflect the views of experts as to what consumers find useful or participative, rather than the consumers’ views on how to positively influence their health outcome(s). In this level of participation the consumer plays a passive role, where they are a source or recipient of information, rather than an active participant. Examples from the data include: the pregnant healthcare worker represents the consumer on maternity service planning issues; the document format marginalises consumer influence in care planning; and, the absence of evidence of feedback or constructive use of consumer feedback. Using Bastian’s (1996) guidelines, Site A’s level of participation activity is still likely to influence consumer health outcome measures favourably.

Site B’s Participatory and Feedback Findings

In completing the environmental walk-through, Site B’s clinical environment shows minimal evidence of participatory and feedback strategies. Site B’s evidence of participative intentions is tabled below (table 4.5).
### Table 4.5 Site B’s Environmental Attributes and Participative Intentions

<table>
<thead>
<tr>
<th>Mission statement</th>
<th>‘Offering convenience and choice for you and your family’ The consultant obstetrician will discuss the options of antenatal care available to you on your initial visit.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer Rep</td>
<td>Yes Two consumer reps on health council <em>No consumer rep at time of research, no planned inclusion of consumer rep.</em></td>
</tr>
<tr>
<td>Generic Service Info</td>
<td>Yes Identified external community service telephone numbers (Human Rights, Anti-Discrimination, Health Rights commission) *A local patient representative was not identified and there was no mechanism for consumer feedback/evaluation identified.</td>
</tr>
<tr>
<td>Condition Specific Info</td>
<td>No</td>
</tr>
<tr>
<td>Pre-Admission Service</td>
<td>No *Jan 2001 pre-admission process initiated</td>
</tr>
<tr>
<td>Provision for record individualising care by clinicians</td>
<td>Yes Antenatal Record / Cooperation card; Maternal Clinical Pathway – Midwife only-variance in progress notes; Progress Notes – Medicine primarily</td>
</tr>
<tr>
<td>Provision for record individualising care by consumers</td>
<td>No *No provision for consumer documentation to be integrated into record, or for participation by the consumer in designing care, provision for consumer to sign pathway on discharge</td>
</tr>
<tr>
<td>Satisfaction surveys/</td>
<td>Yes Patient Satisfaction Survey– <em>Minimal knowledge of content, frequency of distribution, who was responsible and methods of feedback (unit manager)</em></td>
</tr>
<tr>
<td>Patient evaluations</td>
<td></td>
</tr>
</tbody>
</table>

Table 4.5 shows that it is not Site B’s intention to support an active level of consumer participation or a consumer oriented approach to healthcare. Site B’s environmental data reveals that the organisational strategies, from the mission statement down, are not intended to foster active participation or feedback from the consumer. Comparing Site B’s data with Bastian’s consumer participation framework (1996), the level of activity is equivalent to an organisation that intends to educate or use the consumer as a source or recipient of information; therefore at the manipulative level of intent. Using Bastian’s (1996) guidelines, this level of participation activity is likely to have minimal influence on the health outcome measures of the consumer.
Site C’s Participatory and Feedback Findings

In completing Site C’s environmental *walk-through*, there is some evidence of participatory and feedback strategies, suggesting a propensity for an active consumer orientation. Site C’s evidence of participative intentions is tabled below (table 4.6).

Table 4.6 Site C’s Environmental Attributes and Participative Intentions

<table>
<thead>
<tr>
<th>Mission statement</th>
<th>‘Helping people to better health and well-being’; achieved by encouraging individual responsibility for healthcare. Values – A commitment to quality outcomes through proper evaluation of all services; achieved by focussing on healthcare and consumer needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer Rep</td>
<td>Yes Two consumer reps on health council <em>No consumer representative on service planning.</em></td>
</tr>
<tr>
<td>Generic Service Info</td>
<td>Yes  <em>Does not identify patient liaison service or internal/external feedback mechanism for consumers</em></td>
</tr>
<tr>
<td>Condition Specific Info</td>
<td>Yes  <em>Multiple Pathways- only Post-partum Pathway Specific</em></td>
</tr>
<tr>
<td>Pre-Admission Service</td>
<td>No  <em>Admission postnatal ward</em></td>
</tr>
<tr>
<td>Provision for record individualising care by clinicians</td>
<td>Yes  Antenatal Record / Cooperation card; Obstetric Early Discharge Program – Home visit/ history; Pre theatre clinical pathway- Midwife-Special needs / variance; Post Caesarean Section Pathway – Midwife- Special needs / variance; Progress notes- Medicine; Obstetric Discharge Summary</td>
</tr>
<tr>
<td>Provision for record individualising care by consumers</td>
<td>No  <em>No provision for consumer to document individual designing of care.</em></td>
</tr>
<tr>
<td>Satisfaction surveys/ Patient evaluations</td>
<td>Yes  Recently ceased localised service evaluation in preference of an organisational wide approach co-ordinated by a private consultancy. *No feedback from evaluations to clinicians Suggestion forms distributed high profile/ volume locations. Form contains contact number for patient liaison service. <em>Accessing feedback from suggestions – unknown</em></td>
</tr>
</tbody>
</table>

Table 4.6 shows that Site C’s intention is to work towards supporting an active level of consumer participation or a consumer oriented approach to healthcare. Site C’s intention of integrating healthcare provision and service evaluations is considered a step towards facilitating a participative environment. In spite of this propensity, consumer feedback is gained
passively and there is an absence of avenues for consumers to be active participants in their healthcare. In comparing Site C’s participatory intentions with Bastian’s (1996) consumer participation framework, the evidence of consumer activity is between the levels of Restricted Scope and Manipulation. This means that Site C’s evidence of consumer activity fits the descriptors of the consumer either being educated or consulted via token methods. In this healthcare model, Bastian (1996) describes the consumer as being predominantly a passive participant and the level of participation is unlikely to significantly influence consumer health outcome measures.

Summary of Participatory and Feedback Findings

The walk-through method allowed me to observe and experience the environment of each setting and provided sufficient evidence for a comparison of each organisation’s propensity for an ‘active’ orientation. Comparing the descriptive data with Bastian’s (1996) consumer participation framework, the sites fit the Restricted Scope category, with the activity levels ranging between Open Involvement to Manipulation. Site A demonstrates the greatest propensity towards adopting an active orientation, whilst Site B has the greatest propensity for a passive orientation towards maternity care consumers. It is noteworthy that there are discrepancies within each site’s intention and application of participation strategies in the clinical environment. Significantly, not one of the sites could be considered capable of enabling an environment that significantly improved consumer health outcome measures.

In summarising the participatory and feedback findings of Domain One – The Environment, it is apparent that there are inconsistencies between an organisation’s intention to facilitate consumer participation and the practice of it. The absence of effective feedback mechanisms or evidence of collaboration between the organisation, healthcare professional or the consumer are factors that are likely to further compound the disparity. It is also noteworthy, that Bastian (1996) asserts that the possibility of consumer consultation, even in the form of manipulation, may favourably influence consumer outcomes. This suggests that in this study's samples, some
consumers may report an enabling environment in a site that does not necessarily demonstrate participative attributes or the attributes of an ‘active orientation’.

Clinician’s Views on Consumer Participation in Clinical Care

This section of Domain One - The Environment, presents the clinician samples’ self-reported views on practising consumer participation. The two survey questions were detailed in the methods section (pp.125-8). The clinician’s responses will be useful in further understanding each organisation’s orientation to consumers as active participants, but also provide an insight to the level of activity that individual clinicians view to be appropriate. This was a voluntary, self-report survey; hence, not all clinicians responded to every question. The analysis of Site A’s findings are described in detail below. The findings from Site’s B and C underwent identical analysis; however, the findings have been presented in a less descriptive style for reasons of brevity.

Site A’s Clinician’s Views on Consumer Participation in Clinical Care

*Question One* - The first survey question sought each clinician’s views on the appropriateness of the statement that, ‘clinical care standards should be based on what is acceptable to patients’. The frequencies of the complete range of responses are displayed in Table 4.7 and each response has been analysed individually as a discipline and then collectively as a site. For example, in exploring Site A’s very appropriate responses, nineteen midwives (Discipline) responded, and five (5/19 or 26%) considered it very appropriate that clinical standards were based on what was acceptable to patients. In tallying the responses from the thirty-two clinicians eight (8/32 or 25%) in total selected the very appropriate response.
Table 4.7  Clinician Survey: Site A’s Responses to Question One
‘Clinical standards should be based on what is acceptable to patients (consumers)’

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Very Appropriate</th>
<th>Appropriate</th>
<th>Neither</th>
<th>Inappropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (n=8)</td>
<td>1</td>
<td>6</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Midwifery (n=19)</td>
<td>5</td>
<td>9</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Theatre Nurse (n=5)</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total (n=32)</td>
<td>8 (25%)</td>
<td>17 (53%)</td>
<td>5 (16%)</td>
<td>2 (6%)</td>
</tr>
</tbody>
</table>

Table 4.7 shows that from a sample of thirty-two clinicians, the majority (25/32) view it is very appropriate or appropriate that clinical standards should be based on what is acceptable to the patient (consumer). Of the different disciplines, midwives have the greatest variation in responses. Four midwives are undecided, one midwife considers it inappropriate, and fourteen view it appropriate or very appropriate. In contrast, the theatre nurse and medical disciplines show similarities in response to this question.

Question Two - The second survey question seeks each clinician’s agreement or disagreement with the statement that: ‘patients (consumers) should be involved in setting clinical care standards’.

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Strong agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strong disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (n=8)</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Midwifery (n=19)</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Theatre Nurse (n=5)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Total (n=32)</td>
<td>2 (6%)</td>
<td>11 (34%)</td>
<td>7 (22%)</td>
<td>8 (25%)</td>
<td>4 (12%)</td>
</tr>
</tbody>
</table>

Table 4.8 shows that the thirty-two responses are spread across the range of agreement and disagreement. The clinicians are divided between their
agreement (13/32) and disagreement (12/32) with the statement. Twice as many clinicians strongly disagree (4/32) with consumer involvement in setting clinical standards compared to those clinicians who strongly agree (2/32). Seven of the clinicians (7/32) are undecided.

Of the different disciplines, nineteen midwives completed the survey, six of these (31%) agreed with patient involvement in setting clinical care standards and thirteen (69%) did not. Theatre nurses are also unlikely to view agreement with patient involvement. By comparison, the eight doctors who completed the survey reverse the midwife and theatre nurse responses, with five agreeing (63%) with the statement and three disagreeing (37%).

Summary – Site A’s Clinicians’ Views on Consumer Participation in Clinical Care

The sample of clinicians who completed the survey from Site A are generally in agreement that basing clinical standards on what the consumer considers to be acceptable is appropriate. Indeed, 78% of the sample view that it is either appropriate or very appropriate. However, there is disagreement as to whether the consumer should be actually involved in setting the clinical standards, with only 40% of clinicians agreeing with this statement. Hence, the findings suggest that Site A’s clinical care standards are set according to what the clinician views as acceptable to the consumer. The midwife sample is most likely to view that consumers should not be involved in setting clinical care standards. Overall, Site A’s survey findings suggest that individual clinician’s views on consumer involvement in decision making are likely to vary, regardless of the discipline grouping. This variation in views is unlikely to support an active level of participation (partnership) or to improve consumer health outcome measures. The views of this sample of clinicians are congruent with Site A’s restricted capacity to support a consumer oriented environment (p 178).

Site B’s Clinicians’ Views on Consumer Participation in Clinical Care

Question One – Responses to question one of the clinician survey are displayed in Table 4.9. Site B’s responses to the statement, ‘clinical care standards
should be based on what is acceptable to patients’ have been analysed individually and then collectively.

Table 4.9 Clinician Survey: Site B’s Responses to Question One
Clinical standards should be based on what is acceptable to patients (consumers)

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Very Appropriate</th>
<th>Appropriate</th>
<th>Neither</th>
<th>Inappropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (n=9)</td>
<td>1</td>
<td>6</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Midwifery (n=18)</td>
<td>9</td>
<td>6</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Theatre Nurse (n=7)</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total (n=34)</td>
<td>14 (41%)</td>
<td>14 (41%)</td>
<td>5 (15%)</td>
<td>1 (3%)</td>
</tr>
</tbody>
</table>

Table 4.9 shows that this sample of thirty-four clinicians is mostly (28/34) of the view that it is very appropriate or appropriate that clinical standards are based on what is acceptable to consumers. Individually, the disciplines tend to view this statement as appropriate. Three midwives (3/18 or 17%) and two medical (2/9 or 22%) clinicians are undecided in their views, and a theatre nurse (1/7 or 14%) viewed it to be inappropriate.

Question Two - Responses to question two of the clinician survey are displayed in Table 4.10. Responses to the statement, ‘should patients be involved in setting clinical care standards’ have been analysed for Site B as individual disciplines and then collectively as a site.

Table 4.10 Clinician Survey: Site B’s Responses to Question Two
Patients (consumers) should be involved in setting clinical care standards

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Strong agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strong disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (n=9)</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Midwifery (n=18)</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Theatre Nurse (n=7)</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total (n=34)</td>
<td>5 (15%)</td>
<td>13 (38%)</td>
<td>8 (23%)</td>
<td>7 (21%)</td>
<td>1 (3%)</td>
</tr>
</tbody>
</table>

Table 4.10 shows that Site B’s sample of thirty-four clinician’s views are spread across the scale. More clinicians strongly agree (5/34) compared to those who strongly disagree (1/34). Eighteen or 53% of the sample agree to some degree that consumers should be involved in setting clinical standards. By
comparison, sixteen or 47% of the clinician sample are either undecided (8/34), disagree (7/34) or strongly disagree (1/34) with involving the consumer.

As different disciplines, seven out of nine doctors (78%) tend to disagree or be undecided as to whether the consumer should be involved in setting clinical care standards. In opposition to this viewpoint, eleven out of eighteen midwives (61%) and five out of seven theatre nurses (71%) are in agreement with the statement. Interestingly, five midwives (28%) from the sample strongly agree and five disagree with this statement, this disparity suggests that the midwives from Site B’s sample have definite yet conflicting views and that these views are likely to influence consumer involvement in healthcare.

Summary - Site B’s Clinicians’ Views on Consumer Participation in Clinical Care

The findings show that the sample of clinicians surveyed from Site B are mostly of the view that it is appropriate to base clinical standards on what patients (consumers) consider to be acceptable. Consumer involvement in setting clinical standards is however less enthusiastically embraced as a collective viewpoint. The clinicians’ views reflect the environmental data (p.146), where Site B is described as preferring to educate rather than consult consumers in the organisation of healthcare. As a result, the survey findings suggest that Site B’s clinical care standards are likely to be set by the clinician, who has appropriately considered what is acceptable for the consumer. This consideration is likely to occur in isolation from the consumer, particularly in regard to doctor led decision making. The variations of views expressed by Site B’s clinician sample, suggest that the behaviours of clinicians towards engaging consumers in their healthcare, is also likely to vary considerably. An environment such as this is unlikely to favourably influence consumer health outcome measures.

Site C’s Clinicians’ Views on Consumer Participation in Clinical Care

Question One - Responses to question one of the clinician survey are displayed in Table 4.11. Site C’s responses to the statement, ‘clinical care
standards should be based on what is acceptable to patients’ have been analysed individually and then collectively.

Table 4.11  Clinician Survey: Site C’s Responses to Question One  
Clinical standards should be based on what is acceptable to patients (consumers)

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Very Appropriate</th>
<th>Appropriate</th>
<th>Neither</th>
<th>Inappropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (n=10)</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Midwifery (n=18)</td>
<td>4</td>
<td>11</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Theatre Nurse (n=8)</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total (n=36)</td>
<td>13 (36%)</td>
<td>19 (53%)</td>
<td>3 (8%)</td>
<td>1 (3%)</td>
</tr>
</tbody>
</table>

Table 4.11 shows that Site C’s sample of thirty-six clinicians are mostly (32/36 or 89%) of the view that it is very appropriate or appropriate that clinical standards are based on ‘what is acceptable to patients’. Individually, each of the disciplines tends to view the statement as appropriate. The midwife sample has the greatest variation in their responses, ranging from very appropriate to inappropriate, whilst the medical sample is the most consistent with all doctors considering it appropriate.

Question Two- Responses to question two of the clinician survey are displayed in Table 4.12. Responses to the statement, ‘patients should be involved in setting clinical care standards’ have been analysed for Site C as individual disciplines and then collectively as a site.

Table 4.12  Site C’s Clinician Survey Responses Question Two  
Patients (consumers) should be involved in setting clinical care standards

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Strong agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strong disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (n=10)</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Midwifery (n=18)</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Theatre Nurse (n=8)</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Total (n=36)</td>
<td>3 (8%)</td>
<td>10 (28%)</td>
<td>5 (14%)</td>
<td>13 (36%)</td>
<td>5 (14%)</td>
</tr>
</tbody>
</table>

Table 4.12 shows that Site C’s sample of thirty-six clinician’s views are spread across the scale. Thirteen (36%) of the clinicians agree to some degree that consumers should be involved in setting clinical standards, whilst eighteen (50%) disagree to some extent. More clinicians view strong disagreement (5/36) than strong agreement (3/36).
As different disciplines, Site C’s responses show the midwife sample to hold the strongest views in regard to consumer involvement, both in agreement and disagreement. The midwife and the theatre nurse samples are more likely to disagree than agree with the survey statement. The sample’s ten doctors are divided equally between agreement (4/10) and disagreement (4/10) with involving patients in setting clinical care standards.

**Summary- Site C’s Clinicians’ Views on Consumer Participation in Clinical Care**

The survey findings identify that Site C’s sample of clinicians are generally in agreement that it is appropriate to base clinical standards on what consumers consider acceptable. However, the sample is in disagreement as to whether consumers should be involved in setting the clinical standards. This site demonstrates the greatest contrast between the ways that clinicians respond to each of the survey statements. Similar to the other sites, the findings suggest a trend towards clinical care standards being set on what the clinicians view as acceptable to consumers, and that midwives have the strongest and greatest variations in their views about consumer involvement. Overall, Site C’s clinician survey findings are supportive of the environmental data (p.180) where there is a propensity yet minimal opportunity for consumers to be active participants in their healthcare.

**Summary of Clinicians’ Views on Consumer Participation in Clinical Care**

As stated in the introduction, clinical care standards can be described as a consensus that guides the generic design of clinical healthcare (Chapter Three p 127). The standards may be unique for each setting and are often purported to be set within a collaborative process. In Domain One – The Environment, the aim is to explore the views of a sample of clinicians from each of the study’s sites, about what is appropriate in regard to consumer involvement in designing healthcare.

The finding, that is consistent across the three sites, is that there is a lack of consensus within and between clinical disciplines with regard to what is
viewed as appropriate consumer involvement. However, consensus does exist in that the clinicians view it appropriate to consider the consumer when planning healthcare.

As detailed in the methods section, the sampling techniques used in this study limited analysis to the description of the strength of a relationship, rather than as a basis of an inference to a larger population external to this study. The inability to clarify whether in rating appropriate, this means that clinicians are considering the consumer, or that the consumer is actually consulted, is also a limitation of the survey methods. The survey has demonstrated that it is unlikely that the consumer's voice is a determining factor in healthcare; rather, it is the clinician's perception of consumer needs or wishes that influences the setting of clinical care standards, and ultimately the consumer's healthcare experience. A relationship is established between the passive involvement of consumers in healthcare that is implied by the clinicians' responses and Bastian's (1996) description of clinicians acting as experts, advocating what they perceive would be acceptable to the consumer, or clinicians educating consumers as to what is acceptable. This means that the consumer is likely to be a passive participant whose perspectives and concerns are not specifically sought or addressed through the clinical care standards.

These findings will be explored in Chapter Five where the data collected and triangulated from the medical record sample, environment and consumer sample will also be considered.

**Project Data - Organisational Characteristics and Management Orientation**

The purpose of this section of Domain One – The Environment, is to examine the Commonwealth project's findings related to each site's organisational characteristics and management orientation. This allows for comparison, and perhaps verification, of any assumptions or findings that are made based on this study's analysis of each site's environmental data. Having access to the Commonwealth project's data provides an opportunity to compare Domain One's walk-through and clinician survey findings with the findings of research
colleagues who are exploring the same data sources, but using different approaches.

This segment of the Commonwealth project’s data forms the basis of the project leader’s (Ros Sorensen) doctoral study. In describing organisational characteristics, Sorensen states that the three sites are comparable in that they each tend to favour the traditional operational structure of clinical work rather than a more contemporary or collaborative model of healthcare (Sorensen et al 2001). The comparable features include, profession based management structures (including a medical hierarchy with little multidisciplinary management of care) and reporting mechanisms that are predominantly budget and/or cost focused (Sorensen et al 2001). Tables 4.13.1 and table 4.13.2 provides an overview of Sorensen’s work, targeting aspects relevant to the aims of Domain One. The tables are followed by a summary of Sorensen’s (2001) data, identifying the presence or absence of site specific organisational characteristics and describing each site’s management orientation to clinical work. Sorensen’s work (Table 4.13.1 and 4.13.2) will be referred to in Domain One’s data summary, comparing the data interpretations for each site and summarising the impact on the practice of consumer participation.

Table 4.13.1 Sorensen et al (2001) Organisational Characteristics Data Summary

<table>
<thead>
<tr>
<th>Organisational Characteristics</th>
<th>Descriptors of Characteristic</th>
<th>Evidence of Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>P = present; A = absent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Site A</td>
</tr>
<tr>
<td>Structuring of clinical work</td>
<td>Discipline/profession based or Systematised</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>A</td>
</tr>
<tr>
<td>Clinical work management</td>
<td>Medically based or Multidisciplinary focussed</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>A</td>
</tr>
<tr>
<td>Reporting mechanisms</td>
<td>Input (Cost) focused reports Output (Clinical outcome) focussed reports Quality reports</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>A</td>
</tr>
</tbody>
</table>
Table 4.13.2 Sorensen et al (2001) Management Orientation Data Summary

<table>
<thead>
<tr>
<th>Level of Management</th>
<th>Orientation to clinical work</th>
<th>Evidence of Orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>P= present; A= absent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Site A</td>
</tr>
<tr>
<td>Corporate management</td>
<td>Review quality/ adverse events</td>
<td>P</td>
</tr>
<tr>
<td>Clinical directorate</td>
<td>Review Quality</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Review Complaints</td>
<td>P</td>
</tr>
<tr>
<td>Clinical unit</td>
<td>Multidisciplinary review</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Quality reviewed by condition</td>
<td>A</td>
</tr>
</tbody>
</table>

Sorensen’s (2001) data describes Site A’s management as amenable to reviewing healthcare quality, in terms of the technical provision of care and individual complaints. However, Site A lacks ways to feedback ‘quality review’ outcomes into clinical systems or to review quality at the point of healthcare delivery (condition specific review), suggesting that although Site A’s quality strategies appear to be comprehensive; they are unlikely to significantly impact on service provision.

Sorensen’s (2001) data describes quality in Site B as being the sole responsibility of corporate management, with an absence of evidence of quality and outcome measures being a component of clinical reviews or integrated into the delivery of healthcare. Site B’s clinical managers or clinicians are not found to be orientated to reviewing quality, and clinical work practices are only reviewed within individual disciplines.

In contrast to Site B, Sorensen’s (2001) data shows quality in Site C is not the responsibility of corporate management. Site C’s clinical managers are responsible for reviewing complaints, and clinicians undertake a multidisciplinary review of care. Interestingly, Site C’s management is not oriented to reviewing clinical and service quality (Sorensen et al 2001).

In summarising Sorensen’s (2001) organisational characteristic data, each site’s descriptions highlights obvious similarities between them. For example, each site tends to be structured in such a way that clinical work is discipline specific, medically managed and cost focused. Sorensen’s (2001) management orientation data demonstrates that each site has taken a different approach to
distributing, if at all, accountability to reviewing clinical quality. It shows that quality review is independent of the organisational structure of clinical work, meaning that despite demonstrating a management orientation that supports a multidisciplinary review of quality, the structure of clinical work (clinical care) would be identical to organisations that are indifferent to quality review.

**Summary of Domain One – The Environment**

The intention of this first Domain – The Environment, is to describe each site’s capacity to enable a contemporary consumer-oriented healthcare model. Accordingly, each site is examined for evidence of an environment that actively engages and involves consumers in designing their healthcare. The methods used to gather this evidence include a walk-through the clinical setting, reviewing the design of the organisation’s documents and seeking a sample of clinician’s views on consumer participation. Furthermore, for comparative purposes, organisational characteristics and management orientation data collected from the sites have been accessed from the Commonwealth project database. The key findings for each site will now be summarised.

**Site A**

The Environmental Domain data describes Site A as an organisation giving conflicting messages about its intentions about adopting an active consumer orientation into clinical practice.

Site A’s environment demonstrates a propensity for standardisation and participation; however, the evidence I collected highlights a lack of infrastructure to sustain an active level of participation. The Commonwealth project’s organisational characteristics (Sorensen et al 2001) support this interpretation of the data. The potential of the participative attributes highlighted in the environmental data is negated by an organisational orientation that continues to support traditional management and work structures. This orientation minimises avenues for collaboration, communication and consensus. Likewise, Site A’s sample of clinicians reported
ambivalence towards consumer participation. Variations in the clinician’s views on consumer involvement are also likely to override any participative intentions that the organisation had.

In summary, this study’s data describes Site A as having the intention, but not the capacity to generate an environment that facilitates participation. Bastian’s (1996) consumer participation activity framework describes Site A’s level of participation as *tokenistic*, with some potential for influencing consumer health outcome measures. The factors that emerge from the data that are most likely to obstruct this potential are the inconsistency in intentions, views or practices, followed by a lack of leadership and then a lack of ownership in relation to facilitating a *participative* orientation towards healthcare consumers.

Site B

The Environmental Domain data describes Site B as a site that is supportive of the traditional paternalistic medical model of healthcare. There is minimal evidence of organisational strategies designed to guide the site into the contemporary consumer participation approach. Sorensen et al’s (2001) organisational characteristics are supportive of this view.

Interestingly, Site B is not deceitful about its intentions. The consumer is informed from their first contact with the organisation that the medical clinician would decide the availability of healthcare options, and the organisation of clinical care is true to what Bastian (1996) labels as the *manipulation* level of involvement. Site B’s sample of clinicians, in particular medical clinicians, reported alliance with the view that it is appropriate for the consumers’ healthcare needs to be determined by the clinician, reinforcing the paternalistic nature of the healthcare relationship.

Site B does have strategies (consumer survey and representatives) in place that could be identifiable externally as being compliant with State quality and safety recommendations. However, these strategies are unsupported and are of no consequence in the organisation and practice of clinical care.
Site C

The Environmental Domain data describes Site C as demonstrating many of Site A’s characteristics. Site C’s organisational orientation demonstrates a propensity to guide the setting into a more contemporary quality and safety model, but lacks the infrastructure to review the quality of care or to seek meaningful input from the consumer. Another barrier to adopting a more contemporary approach to the delivery of healthcare was the clinicians’ tendency to view consumer involvement in setting clinical care standards disapprovingly, preferring to orientate themselves with more traditional approaches.

One of Site C’s unique qualities is its focus on providing evaluation and feedback mechanisms. This site shows evidence of a number of mechanisms to obtain feedback from consumers. However, there is minimal, if any, evidence of the feedback impacting on clinical care or being disseminated to the clinicians. This process (as with other strategies intended to facilitate participation), are described using Bastian’s (1996) consumer participation activity levels, as being either restrictive or manipulative. This means that it is unlikely that the strategies would or could have any impact on consumer health outcome measures.

Summary Domain One – The Environment

In essence, Domain One’s data describes each of the study’s sites as lacking the capacity to engage consumers actively in participation strategies. A lack of coordination, consensus and consistency between the intentions of the organisation and the clinicians are recurring findings. An absence of supportive infrastructure, as demonstrated by the fact that each organisation continues to function within traditional medical frameworks, emerges as a factor that is worthy of further investigation. The data suggests that the environment’s orientation is a contributory factor to the predominantly passive or superficial level of consumer participation identified in each site.
These findings will be explored in detail in the triangulation of the study’s findings in Chapter Five. The second Domain of the study, the clinician, will now be presented.
Domain Two - The Clinician

As detailed in Chapter Two (pp.17-8), in 2001 McMillan described the contemporary healthcare professional as someone who is knowledgeable, and willing to collaborate and reconceptualise the organisation of his/her clinical practice into a collaborative model, one where consumers and colleagues are viewed as partners in healthcare responsibility.

In this domain of the study, the intention is to examine the samples of clinicians’ views on the participativeness or collaborative attributes of their clinical practice. The responses from the clinician sample from each site are categorised into his/her professional discipline (i.e. medicine, midwifery or theatre nurse), with each survey being examined and compared for associations or differences within their discipline grouping and site, as well as collectively as the healthcare workforce.

Building on from the lack of coordination, consensus and consistency alluded to in the first Domain, the views and behaviours of the clinicians will also be examined for contradictions between stated intention and actual practice.

Clinician Demographics

Each site’s demographic data (reported in the clinician survey) is examined for factors that might influence the clinician’s knowledge and views, and therefore how they respond to the survey questions. Chapter Three clearly details this study’s methods (p.135). In brief, to approximate each clinician’s capacity to be knowledgeable of contemporary healthcare practices, each response is classified into discipline grouping, and then into modal frequency and percentages of modal frequency, for the demographic variables tertiary qualifications or permanent employment. For example, in site A, thirty-two clinicians completed the survey and eight of these (25%) are doctors who reported having tertiary qualifications (100%). Six of these (75%) reported being permanent employees of the organisation. Table 4.14 displays the demographic data of the clinicians from each site.
Table 4.14 Clinician Sample’s Self Report Demographic Data

<table>
<thead>
<tr>
<th>Site and Discipline</th>
<th>Response Distribution of Sample</th>
<th>Variable Tertiary Qualification</th>
<th>Variable Permanent Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Modal Freq (Percent of Modal Freq)</td>
<td>Modal Freq (Percent of Modal Freq)</td>
<td>Modal Freq (Percent of Modal Freq)</td>
</tr>
<tr>
<td><strong>Site A</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>8/32 (25%)</td>
<td>8/8 (100%)</td>
<td>6/8 (75%)</td>
</tr>
<tr>
<td>Midwifery</td>
<td>19/32 (59%)</td>
<td>11/19 (58%)</td>
<td>16/19 (84%)</td>
</tr>
<tr>
<td>Theatre Nurse</td>
<td>5/32 (16%)</td>
<td>2/5 (40%)</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td><strong>Site B</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>9/34 (26%)</td>
<td>9/9 (100%)</td>
<td>9/9 (100%)</td>
</tr>
<tr>
<td>Midwifery</td>
<td>18/34 (53%)</td>
<td>12/18 (67%)</td>
<td>18/18 (100%)</td>
</tr>
<tr>
<td>Theatre Nurse</td>
<td>7/34 (20%)</td>
<td>7/7 (100%)</td>
<td>6/7 (86%)</td>
</tr>
<tr>
<td><strong>Site C</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>11/38 (29%)</td>
<td>10/11 (91%)</td>
<td>9/11 (82%)</td>
</tr>
<tr>
<td>Midwifery</td>
<td>19/38 (50%)</td>
<td>14/19 (74%)</td>
<td>16/19 (84%)</td>
</tr>
<tr>
<td>Theatre Nurse</td>
<td>8/38 (21%)</td>
<td>5/8 (62%)</td>
<td>8/8 (100%)</td>
</tr>
</tbody>
</table>

Table 4.14 presents demographic data of the clinicians from each site categorised into discipline groupings. The distribution of the discipline groupings within the clinician samples is shown to be comparable across the sites. Analysis of the clinician demographic data is considered reliable, provided no inferences are drawn as to the incidence of a particular response item in a clinical site or clinical discipline. This means that this sampling is useful in describing the strength of a relationship or difference, rather than as a basis of inference to a larger population.

The finding of a predominantly tertiary acquired education in the study’s healthcare workforce, in reference to the nursing/midwifery samples, implies the potential for a shift from traditional vocational training that fostered medical hegemony (Crookes 1992) towards a more contemporary professional and consumer collaborative model of healthcare. This same assumption however, was unable to be made in relation to the medical clinicians because doctors have historically acquired their professional status through tertiary-based education. Therefore, the medical clinician’s tertiary qualifications
cannot be used to imply recent exposure to, or the likelihood of an awareness of, contemporary healthcare views.

The terms of the clinician’s employment being predominantly full time or part time, may not allow for the implication of a standardised approach to work; however, it did allow for the suggestion that the clinicians would have had the opportunity to be oriented to the organisation, its policies and procedures.

In summary, the clinicians’ demographic data shows that the midwife and theatre nurse participants vary in their educational and training background compared to medical clinicians, and that overall, the workforce is reasonably stable (i.e. permanent employees). In the context of this Domain’s objectives, this means that it is likely that the clinicians’ knowledge and views of contemporary healthcare practices will vary. However, clinicians are likely to be aware of how his/her site organises and communicates clinical care. The relationship between the clinician’s demographic data and the practice of consumer participation at the frontline of healthcare is considered in Chapter Five’s data triangulation.

**Documentation of Healthcare**

Domain One - The Environment identifies the documents from each site that project the trajectory of healthcare for elective caesarean section consumers. These documents are commonly known as *clinical pathways* or *care maps* and serve different purposes in each site, and for each discipline. Despite this, each site clearly states that their *clinical pathway* is designed to guide clinical practice and each site’s policy supports the pathway as a useful tool for organising clinical care.

In Domain Two - The Clinician, closed questions are used to gain an insight into:

- the awareness of the standardised document for their site
- the use of the document to organise care
the interpretation of their accountability to document variances that may have occurred from the document.

In brief, the responses from each site were tabled to determine the proportion of clinicians who respond always or frequently to these questions.

Site A’s Documentation of Healthcare

The Environmental data (p.178) shows that Site A has a multidisciplinary clinical pathway specifically designed for the caesarean section healthcare trajectory. This clinical pathway supports the individualising of clinical care through recording special needs and variations from the pathway’s projected trajectory.

Table 4.15 shows how the sample of clinicians from Site A respond to awareness of the clinical pathway, and the frequency of the responses regarding always or frequently using and recording variances from the pathway. For example, when viewing the medical (Discipline) responses, seven of the eight clinicians know the pathway exists to organise care (Question 1), of these seven, none of them always/frequently utilise the pathway (Question 2), and none always/frequently record any variances from the pathway (Question 3).

Table 4.15 Clinician survey: Site A’s ‘Documentation of Healthcare’ responses

<table>
<thead>
<tr>
<th>Site A Discipline of Survey Sample</th>
<th>Question 1. Yes, Aware of a form that sequenced care</th>
<th>Question 2. If yes, always or frequently used the form to organise care</th>
<th>Question 3. Always or frequently recorded variances from the form sequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>7/8</td>
<td>0/7</td>
<td>0/7</td>
</tr>
<tr>
<td>Midwife</td>
<td>17/19</td>
<td>16/17</td>
<td>14/17</td>
</tr>
<tr>
<td>Theatre Nurse</td>
<td>3/5</td>
<td>0/3</td>
<td>1/3</td>
</tr>
<tr>
<td>Total</td>
<td>27/32 (84%)</td>
<td>16/27 (59%)</td>
<td>15/27 (56%)</td>
</tr>
</tbody>
</table>

Reading Table 4.15, question one reveals that collectively, twenty-seven (84%) of the clinicians know that the medical record includes a form that organises ECS care. Of those twenty-seven, sixteen (59%) always/frequently use the form when organising care and fifteen (56%) always/frequently record
variations from the forms specified sequences. In other words, upwards of 40% of the clinicians surveyed, who claim awareness of the form, consciously elect not to use or document variances from the form, or are aware of the form, but are not aware of their responsibilities.

Examining the practices of Site A’s clinicians within their disciplines, from the eight doctors in the sample, seven state they know of the form and one did not. From the seven doctors who claim to be aware of the form, not one states that they always/frequently use or document variances in clinical care. Similarly, from the five theatre nurses in the sample, three are aware of the form, no one uses the form to organise care and only one theatre nurse reports that she/he records variances from the form.

In contrast, from the nineteen midwives who respond, seventeen claim to be aware of the form, sixteen of the midwives who know of the form always/frequently use it and fourteen midwives always/frequently record variances from the form.

Summary of Site A’s Documentation of Healthcare Findings

The environmental data’s description of a multidisciplinary clinical pathway document supports the survey findings that most clinicians are at least aware of a form that sequences clinical care. However, when translating awareness to practice, a trend emerges where individual clinicians declare whether they use or record variations on the form when planning clinical care. The shift from collective awareness to individual behaviours suggests that clinicians’ awareness of the multidisciplinary intent of the form is inaccurate, or clinicians are consciously ignoring their responsibilities. It must also be acknowledged that the absence of the operating theatre nurse’s contribution to the healthcare trajectory within the clinical pathway document is considered a limitation to the design of the form, and may account for the theatre nurses’ responses.

Variation in the clinicians’ responses to how they organise care and communicate alterations from the expected sequences of healthcare, suggests
that Site A’s clinical care is not standardised or oriented towards collaboration. The findings do suggest that communication between and within clinical disciplines, and potentially with the consumer, are likely to be ineffectual.

Significantly, the clinicians’ tendency to state that they did not always/frequently use or record in an authorized document even though they are aware of one, suggests that they may not be aware of the legal implications of such practice. Potentially, the clinicians may be accused of negligence in regard to their legal responsibility to the consumer, their employing organisation and their professional code of ethics. The response trend also implicates negligence on behalf of the healthcare organisation, because it is the organisation’s responsibility to enforce and regulate their employees’ practices in relation to medical record legal requirements.

For the purposes of this study, the responses to the survey questions by clinicians in Site A implies that if a documentation audit is completed on the healthcare records of the consumers cared for by this sample, it is likely that midwifery documentation would dominate the pathway. However, overall the pathway (clinical care sequences) would be incomplete, with minimal evidence of clinical variations being recorded or evaluated. This prediction is explored in the triangulation of the study findings in Chapter Five.

Site B’s Documentation of Healthcare

The environmental data (p.180) illustrates that documents in Site B are not integrated and reflect the traditional medical model of healthcare that the organisation offers. Site B has a clinical pathway that sequences caesarean section care; however, only midwifery care is described. Medical clinicians record the provision of healthcare in the unstructured progress notes. They have the authority to alter the clinical pathway, but are not required to record on the document the variations from the projected trajectory.

Table 4.16 shows how the sample of clinicians from Site B rates their awareness of a form that sequences care. For those who are aware of this form, the
frequency of the response *always* or *frequently* for using the form and recording variances from the care sequence is presented.
Table 4.16 Clinician survey: Site B’s ‘Documentation of Healthcare’ responses

<table>
<thead>
<tr>
<th>Site B</th>
<th>Q1. Yes, Aware of a form that sequenced care</th>
<th>Q2. If yes, always or frequently used the form to organise care</th>
<th>Q3. Always or frequently recorded variances from the forms sequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discipline of Survey Sample</td>
<td>Q1</td>
<td>Q2</td>
<td>Q3</td>
</tr>
<tr>
<td>Medical</td>
<td>3/9</td>
<td>1/3</td>
<td>0/3</td>
</tr>
<tr>
<td>Midwife</td>
<td>14/18</td>
<td>12/14</td>
<td>9/14</td>
</tr>
<tr>
<td>Theatre Nurse</td>
<td>5/7</td>
<td>0/5</td>
<td>1/5</td>
</tr>
<tr>
<td>Total</td>
<td>22/34 (65%)</td>
<td>13/22 (59%)</td>
<td>10/22 (45%)</td>
</tr>
</tbody>
</table>

Reading Table 4.16, question one reveals that twenty-two (65%) clinicians know that the medical record includes a form to organise ECS care. Thirteen (59%) of those always/frequently use the form when organising care and ten (45%) always/frequently record variations from the form’s specified sequences. In other words, similar to Site A, upwards of 40% of the clinicians surveyed, who claim awareness of the form, consciously elect not to use or document variances from the form, or are aware of the form, but not their responsibilities in relation to the form.

The clinicians’ views and behaviours are also examined within their discipline groupings. Of the nine doctors, three know of such a form, one doctor always/frequently uses the form when organising care, but none of the doctors recorded variances from the form’s projected sequence of healthcare. Of the seven theatre nurses in the sample, five are aware of the form; however, no-one always/frequently uses the form to organise care and only one nurse records variances from the forms sequences. Of the eighteen midwives who responded, four are not aware of the form, two who know of the form did not always/frequently use it and five who know of the form, do not record variances from the specified clinical processes. So on balance, regardless of the purpose or focus of the form, Site B’s clinicians tend not to record variances from the form. This means that even though a clinician may be aware or use the form to organise care, it is unlikely that the form would be useful in planning healthcare or communicating variances in the consumer’s healthcare trajectory.
Summary of Site B’s Documentation of Healthcare Findings

The environmental data’s description of Site B as fostering a traditional, discipline specific orientation to the management of clinical work and a lack of accountability to review clinical care quality is supported by the clinicians’ views and behaviours.

Despite over half of the clinicians stating an awareness of a form or pathway that sequences clinical care, the form itself only sequences midwifery care. This means that Site B’s theatre nurse and medical clinicians’ practices are not detailed in the form. Therefore, similar to those in Site A, the responses by clinicians in Site B tend to suggest a lack of consensus or accountability in regard to the form or the recording of clinical variances. Also similar to the results from Site A, the variations in practices within and between the disciplines would have to marginalise the effectiveness of any communication on a professional level and potentially with the healthcare consumer.

The documentation practices highlighted in this survey have legal ramifications for the individual clinician, their profession and the employing organisation. Negligence has been highlighted as an issue of concern in Site A, and is also relevant to Site B.

For the purposes of this study, Site B’s survey sample is made up of clinicians who had documented in the site’s medical record sample. Based on the self reported behaviours of this sample, it is likely that a documentation audit of Site B’s clinical pathway would find the document incomplete; furthermore, the medical record is unlikely to contain evidence of doctors, midwives and theatre nurses communicating or referring to each other’s clinical practices. This assumption is further explored in the data triangulation in Chapter five.

Site C’s Documentation of Healthcare

The environmental data (p.181) shows that Site C has numerous documents for individual purposes (e.g. early discharge; pre-theatre; post caesarean; obstetric discharge) and that these documents tend not to be integrated. Similar to Site
B, Site C has clinical pathway documents that sequence caesarean section care; however, only midwifery care tends to be described.

Site C’s survey responses regarding the awareness of a form that sequences care are set out in Table 4.17. For those who claim to be aware of the form, the frequency of the response always or frequently for using the form and recording variances from the care sequence is shown.

Table 4.17 Clinician survey: Site C’s ‘Documentation of Healthcare’ responses

<table>
<thead>
<tr>
<th>Site C</th>
<th>Yes, Aware of a form that sequenced care</th>
<th>If yes, always or frequently used the form to organise care</th>
<th>Always or frequently recorded variances from the forms sequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discipline of Survey Sample</td>
<td>6/11</td>
<td>0/6</td>
<td>0/6</td>
</tr>
<tr>
<td>Medical</td>
<td>16/19</td>
<td>14/16</td>
<td>13/16</td>
</tr>
<tr>
<td>Midwife</td>
<td>2/8</td>
<td>1/2</td>
<td>1/2</td>
</tr>
<tr>
<td>Theatre Nurse</td>
<td>Total 24/38 (63%)</td>
<td>15/24 (62%)</td>
<td>14/24 (58%)</td>
</tr>
</tbody>
</table>

The data in Table 4.17 shows that twenty-four of the thirty-eight clinicians (63%) in Site C are aware that a form to organise caesarean section care exists. Of those twenty-four, fifteen (62%) always/frequently use the form when organising care and fourteen (58%) always/frequently record variations from the form’s specified sequences. In other words, similar to those in Sites A and B, upwards of 40% of the clinicians surveyed, who claim awareness of the form, admit that they do not use or document variances from the form.

The clinicians’ views and behaviours were also examined within their discipline groupings. For example, Site C had eleven doctors respond, six of them stated they knew of the form, but none always/frequently used the form when organising care or recorded variations from the projected healthcare sequence. Similarly, from the eight theatre nurses who responded, two were aware of the form; however, only one claimed to always/frequently use the form to organise care or reported that she/he recorded variances from the form.
An awareness, yet lack of understanding of the purpose of the pathway document in Site C by the doctors and theatre nurses cannot be considered unexpected, because as with Site B, the form only sequences midwifery practice. However, from the nineteen midwives who responded from Site C, three do not know the form exists, two who know of the form, did not always/frequently use it and three midwives who know of the form do not record variances from the specified clinical processes. So, not unlike the Site A and B survey responses, Site C’s data suggests that awareness of the form does not necessarily correlate with a tendency to use the form. Likewise, just because a site can demonstrate that they have a document that sequences clinical care, does not guarantee that clinical care is sequenced.

Summary of Site C’s Documentation of Healthcare Findings

Site C’s survey data demonstrates that 63% of clinicians in the survey are aware of the form. This is similar to Site B, except the proportion of doctors aware of the form is greater in Site C. The data accommodates Domain one’s assumption of a propensity for the organisation in Site C to be more collaborative and standardised than Site B. However, also similar to that in Site B, the clinical pathway only sequences midwifery care; this attribute of the pathway essentially contradicts any sense of uniformity that the data suggests.

Not dissimilar to Site B’s findings, the survey results have identified that any inconsistency in the practices of the clinical disciplines may be accounted for by the design of the documents. It may be unwarranted to expect a collaborative approach to healthcare design, if the documents that sequence healthcare are exclusive of the disciplines that provide care. Obviously, effective communication and multidisciplinary reviews of clinical practices, initiatives linked to improving the practice of consumer participation in healthcare, are likely to be adversely influenced when clinicians are not given the opportunity to ‘read from the same page’.

Summary of Documentation of Healthcare across the Three Sites
The survey’s findings across the three sites indicate that most clinicians claim to be aware of a form that sequences caesarean section healthcare. This supports the assumption made earlier in regard to the demographic data, that it is likely that the clinician samples have been orientated to the organisation of care.

A review of the forms used to organise care at each of the sites identifies that: Site A’s form includes the multidisciplinary team’s contribution to the care path and provides for individuals (regardless of discipline) to document completion of key tasks; Site B and C’s forms only defined midwifery care processes. Nonetheless, it is important to note that not one of the forms reviewed in this study include the theatre care sequences within their projected trajectory. This omission makes it questionable as to the comprehensiveness of the forms, their capacity to facilitate coordination or communication of healthcare, or the ability to meet the legal requirements of a medical document.

With the pathways tending to detail midwifery care, it is not surprising that midwives are more likely than medical or theatre nurse clinicians to always/frequently claim to use the form when organising care. However, even when aware of the form, midwife respondents did not express that they always use the form. Recording variances from the form’s sequences is the least likely to be noted as a frequent behaviour by the clinicians. Drawing on responses from clinicians in this study in order to inform a review of clinical care, it is evident that an audit of the clinical pathway is likely to be an incomplete record of the provision of care and an ineffective tool to capture the multidisciplinary features of caesarean section healthcare.

In summary, the survey findings suggest that clinical pathway documents, evident in each medical record sample, are unlikely to:

- accurately represent the clinical care provided
- have any impact on clinicians’ behaviours
be an indicator of evaluated clinical practice

can enable the active participation of consumers

The clinicians’ behaviours and views indicate that the relationship between
awareness and practice of a standardised sequence of healthcare for caesarean
section consumers is fragile. Importantly, awareness does not translate into a
sense of accountability to; reference documents designed to standardised
clinical care; use such documents to monitor the delivery of healthcare; or
communicate in such documents the completion of care. In effect, the
organisation of clinical care, regardless of the sites’ intention of being
multidisciplinary in care provision or not, continues to be practiced in
isolation rather than in collaboration between clinical disciplines. The data
thus far indicates a relationship between each site’s environmental attributes
and the clinician’s behaviours.

It is noteworthy that the documentation behaviours described by the clinicians
suggests that an absence of documentation within an audit of the medical
record should not be automatically discounted as an oversight or lack of
awareness on behalf of the clinician. Rather, the clinicians know when they have
not completed specific documents. This assertion has significance for this
study, and is explored further in Chapter Five’s data triangulation.

**Provision of Consumer Information**

With the study design targeting the elective surgical procedure elective
caesarean section; it is reasonable to consider that information sharing
between the healthcare provider and the consumer is routine practice. The
study’s methodology related to examining the information sharing behaviours
of clinicians is detailed in Chapter Three (p.138).

This bank of questions is titled Patient Involvement (Appendix A). Essentially,
the survey questions are designed to elicit routine practice in regard to
providing consumers with information about their care for an elective
caesarean section. For this study’s purpose routine practice is determined by
the clinician reporting that they always or frequently use each site's information sheet (which outlines what the consumer should expect as part of their routine clinical care) when informing consumers about their care. Each site’s intention for providing condition-specific information to consumers is detailed in Domain One (pp.178-81).

Site A’s Provision of Consumer Information

The availability of an information sheet that replicates the standardised processes of their ‘clinical pathway’ in Site A, was identified in Domain One. The information sheet is designed to walk the woman (consumer) through the healthcare processes from pre-admission to discharge, describing the roles of the various clinical disciplines involved in the projected healthcare trajectory.

The proportion of the clinicians who indicated an awareness of Site A’s information sheet and the frequency of the responses always or frequently for using this sheet in their clinical practice is set out below (Table 4.18).

Table 4.18 Clinician survey: Site A’s Awareness and Use of an Information Sheet

<table>
<thead>
<tr>
<th>Site A Discipline of Survey Sample</th>
<th>Yes, Aware of Information Sheet</th>
<th>If yes, always or frequently used Information Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>6/8</td>
<td>2/6</td>
</tr>
<tr>
<td>Midwife</td>
<td>15/19</td>
<td>9/15</td>
</tr>
<tr>
<td>OT Nurse</td>
<td>4/5</td>
<td>1/4</td>
</tr>
<tr>
<td>Total</td>
<td>25/32 (78%)</td>
<td>12/25 (48%)</td>
</tr>
</tbody>
</table>

shows that twenty-five (78%) of the thirty-two clinicians are aware of an information sheet that outlines what the consumer should expect as part of her routine clinical care. Of these twenty-five, twelve (48%) proclaim to always/frequently use the information sheet when educating consumers about what to expect.

Examining the practices of clinicians in Site A as discrete disciplines, six of the eight doctors are aware of the information sheet; however, from those six
only two always/frequently use the sheet in their clinical practice. Of the nineteen midwives in the sample, fifteen are aware of the information sheet and nine always/frequently use the sheet. Four of the five theatre nurses are aware of the information sheet, and only one always/frequently uses the sheet in their clinical practice.

Summary - Site A’s Provision of Consumer Information

Despite having a generalised awareness of an information sheet, the use of the sheet by clinicians in Site A is inconsistent. This suggests inconsistency in the information provided to consumers about what to expect as routine care. Consequently, there is potential for contradictions in information content or delivery methods, and thus marginalising the consumer’s participation in designing their healthcare.

This survey did not ask Site A’s clinicians why they did not use the specifically prepared information sheet. However, in reference to Site A’s Environment data (p.178) and the clinicians’ earlier responses to the questions relating to the documentation of healthcare (p.199), the sheet may not be used because the clinicians are aware that the sheet simply replicates the token participation attributes evident in the organisation’s orientation, and is unlikely to reflect the consumers’ actual healthcare trajectory.

Site B’s Provision of Consumer Information

Domain One’s Environment data describes Site B as missing a condition specific information sheet that is endorsed by the organisation. Site B’s clinicians confirmed the absence of an information sheet about what to expect as routine care. However, the doctors did claim a preference for using the Royal Australian College of Obstetricians and Gynaecologists pamphlet on caesarean section to assist them in educating consumers about the surgical procedure.

Table 4.19 identifies the proportion of clinicians in Site B who are aware of an information sheet and the frequency of the responses always or frequently to using the information sheet in their clinical practice.
Table 4.19 Clinician survey: Site B’s Awareness and Use of an Information Sheet

<table>
<thead>
<tr>
<th>Site B Discipline of Survey Sample</th>
<th>Yes, Aware of Information Sheet</th>
<th>If yes, always or frequently used Information Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine</td>
<td>5/9</td>
<td>3/5</td>
</tr>
<tr>
<td>Midwife</td>
<td>2/18</td>
<td>2/2</td>
</tr>
<tr>
<td>OT Nurse</td>
<td>3/7</td>
<td>1/3</td>
</tr>
<tr>
<td>Total</td>
<td>10/34 (29%)</td>
<td>6/10 (60%)</td>
</tr>
</tbody>
</table>

That collectively, ten (29%) of the clinicians are aware of an information sheet that outlines what consumers should expect as part of their routine clinical care. Of those, six always/frequently use the information sheet in their clinical practice.

Examining Site B’s clinicians as discrete disciplines, five of the nine doctors are aware of an information sheet; however, only three of them always/frequently use the sheet in their clinical practice. Of the eighteen midwives, only two are aware and always/frequently use the information sheet. From the seven theatre nurses, three are aware of the information sheet and only one always/frequently uses the sheet in their clinical practice.

Summary of Site B’s Provision of Consumer Information

The findings from the survey of clinicians as Site B support the Environmental data, in that the responses describe a medical focus to information sharing, and also the absence of a standardised or collaborative method of providing information to consumers about what to expect as routine care. The doctors’ preferences for profession specific clinical information suggest that educative and directive intentions motivate their behaviours, rather than information sharing. Furthermore, it can be assumed that the clinical disciplines are nonplussed about why they need an information sheet, as they are aware that the organisation of clinical care is unlikely to be influenced by the consumer’s involvement.

Site C’s Provision of Consumer Information
In the Environmental data of Domain One, Site C is described as having a generic information booklet and a caesarean section information booklet available for the consumer. The generic information booklet can be found in the antenatal clinic and the caesarean section information booklet is distributed on the day of operation by the midwives. In addition to the organisation’s booklets, the medical clinicians also refer to the Royal Australian College of Obstetricians and Gynaecologists pamphlets on caesarean section and epidural and spinal anaesthesia to assist in ‘educating’ consumers in their practices.

Table 4.20 identifies the proportion of clinicians at Site B who are aware of an information sheet and the frequency of the responses always or frequently to using the information sheet in their clinical practice.

Table 4.20 Clinician survey: Site C’s Awareness and Use of an Information Sheet

<table>
<thead>
<tr>
<th>Site C Discipline of Survey Sample</th>
<th>Yes, Aware of Information Sheet</th>
<th>If yes, always or frequently used Information Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>8/11</td>
<td>4/8</td>
</tr>
<tr>
<td>Midwife</td>
<td>15/19</td>
<td>14/15</td>
</tr>
<tr>
<td>OT Nurse</td>
<td>2/8</td>
<td>2/2</td>
</tr>
<tr>
<td>Total</td>
<td>25/38 (66%)</td>
<td>20/25 (80%)</td>
</tr>
</tbody>
</table>

Table 4.20 shows that from the thirty-eight responses, twenty-five (66%) clinicians from Site C are aware of an information sheet that outlines what the consumer should expect as part of their routine clinical care. Of those, twenty (80%) always/frequently use the information sheet when educating consumers about their care.

Examining these responses as discrete disciplines, eight of the eleven doctors are aware of an information sheet; however, only four of them always/frequently use the sheet in their clinical practice. Of the nineteen midwives, fifteen are aware and fourteen always/frequently use the information sheet. From the eight theatre nurses, two are both aware of the information sheet and always/frequently use the sheet in their clinical practice.
Summary of Site C’s Provision of Consumer Information

The survey data describes clinicians from Site C as predominantly aware of a sheet that provides consumers with information about what to expect as routine care and that those who know of the sheet are likely to use it in clinical practice. The clinicians’ responses support the Environmental data’s description of Site C as favouring information mechanisms such as information sheets, evaluation and feedback methods. The clinicians’ awareness and use of an information sheet suggests that this may be routine practice for these clinicians. The clinicians’ views and behaviours are likely to have enhanced the consumer’s capacity to participate in decision making. However, interpretation of the survey data as representative of a uniformed approach towards information sharing is limited due to the variations in the availability and design of consumer information sheets.

Summary of Provision of Consumer Information across the Three Sites

In this section of the study, the clinicians’ awareness of an information sheet for consumers and the use of these sheets in their clinical practice have been examined. The findings have identified that in general there are inconsistencies in regard to the clinicians’ claims of an awareness and their use of information sheets in clinical practice. The data implies that information sharing, using a standardised source, is unlikely to be usual practice, and many of the clinicians who claim to be aware of an information sheet also report their use to be inconsistent.

Considering the inference that information sharing is a practice that is linked to standardisation, an attribute that has been associated with consumers feeling able to actively participate in decision making processes, the findings raise doubt about the level of consumer participation that is likely to be evident within the study sites. The data suggests that across the sites, clinicians tend to control the sharing of information rather than taking a partnership approach. Site A is the most likely to have a multidisciplinary awareness of their information sheet, while Site C is the most likely to
always/frequently use the information in their clinical practice. The lack of awareness or use of an information sheet at all by the clinicians at Site B demonstrates a traditional paternalistic orientation towards healthcare consumers. The variations in the practice of information sharing with consumers amongst the clinicians suggest that this practice is not included in the sites’ generic workforce orientation processes or at the clinical unit level.

**Communicating ECS Care**

The question relates to communicating ECS care was useful for Domain Two because it establishes the possibility of congruence in how the clinical disciplines, collectively and individually, know or found out what needs to be done next in the ECS healthcare trajectory. Furthermore, the survey responses will assist in understanding whether the clinicians consider the medical record to be a reliable information source. Chapter Three (pp140-41) clearly explains that the rating of *always* or *frequently* for a particular method of communication, means that the clinician considers this method to be *routine* in their clinical practice.

**Site A’s Communicating ECS Care**

The clinicians’ *always* or *frequently* responses for each of the six communication statements from Site A are recorded in Table 4.21. It is noteworthy that the clinicians are able to rate each statement or only respond to methods they identify with. For example, when we view the medical disciplines’ *always* or *frequently* responses to the first two statements, from the six doctors who responded to this statement, two *routinely* find out what has to be done next by information transmitted verbally in ward rounds or shift change; and from the seven doctors who responded to the occupational protocols/guidelines statement, only one doctor *routinely* uses this method.

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Verbal/ward</th>
<th>Protocol guideline</th>
<th>Medical record</th>
<th>Knowing</th>
<th>Talking with</th>
<th>Clinical pathwa</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.21 shows that in total, the *routine* practice for determining what needs to be done next for an ECS consumer in Site A is to access the medical record (84%). This preference is followed by talking with the woman (67%) and occupational protocols/guidelines (62%). As discrete disciplines, the responses indicate that doctors *routinely* access the medical record or talk with the woman. Nurse/midwife responses are spread across every method; however, deciding what needs to be done next is more likely to be determined by accessing the clinical pathway followed closely by the medical record. Theatre nurses are most likely to *routinely* access their occupational protocols/guidelines, followed closely by *knowing* the individual doctor’s preferences.

**Summary of Site A’s Routine Communication of ECS Care**

The findings indicate that the medical record is the most common tool sought by Site A’s clinicians, across all disciplines, when determining a consumer’s progress through the hospital continuum of care or when deciding what needs to be done next for ECS care. The tendency to refer to the medical record for details about the consumer’s healthcare experience raises several possibilities; that is, clinicians consider the medical record to be an accurate representation of the consumer’s experience; referring to the medical record is the traditional thing to do; or perhaps the medical record is a socially desirable (i.e. correct) answer to give.
Viewing the clinicians’ responses within their individual disciplines, strongly suggests that each discipline has commonality in how they *routinely* know or communicate ECS care. The fact that each discipline has a preferred method of communicating creates an obstruction for cross discipline communication and therefore the co-ordination of consumers’ healthcare in Site A. The implications of the data on the practice of consumer participation are further explored in the data triangulation (Appendix G).

**Site B’s Communicating ECS Care**

The clinicians’ responses of *always* or *frequently* for each of the six communication statements are presented in Table 4.22.

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Verbal /ward rounds</th>
<th>Protocol guidelines</th>
<th>Medical record</th>
<th>Knowing individual Doctor</th>
<th>Talk with woman</th>
<th>Clinical pathway</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>6/9</td>
<td>4/9</td>
<td>6/9</td>
<td>5/9</td>
<td>4/9</td>
<td>0/8</td>
</tr>
<tr>
<td>Nurse/Midwife</td>
<td>16/18</td>
<td>14/18</td>
<td>17/18</td>
<td>13/17</td>
<td>13/18</td>
<td>16/18</td>
</tr>
<tr>
<td>OT Nurse</td>
<td>5/7</td>
<td>4/7</td>
<td>5/7</td>
<td>6/7</td>
<td>6/7</td>
<td>0/7</td>
</tr>
<tr>
<td>Total</td>
<td>27/34 (79%)</td>
<td>22/34 (65%)</td>
<td>28/34 (82%)</td>
<td>24/33 (73%)</td>
<td>23/34 (68%)</td>
<td>16/33 (48%)</td>
</tr>
</tbody>
</table>

Table 4.22 shows that in total, the *routine* practice for determining what needs to be done next for an ECS consumer in Site B is to access the medical record (82%). This method is followed by verbal/ward rounds (79%) and knowing the individual doctor’s preferences (73%). As discrete disciplines, the responses are spread across each of the communication methods. Doctors tend to communicate patient care via the medical record and verbal/ward rounds, nurse/midwives are more likely to access the medical record followed closely by the clinical pathway and verbal/ward rounds. Theatre nurses are more likely
to include knowing the individual doctor’s preferences and talking with the woman as their methods of choice.

Summary of Site B’s Communication of ECS Care

Site B’s clinicians prefer to access the medical record when determining a consumer’s progress through the hospital continuum of care. Similar to that of Site A, this finding raises the question as to what the preference for the medical record actually represents. Also, similar to the responses given by clinicians from Site A, clinicians from Site B indicate that apart from the medical record, there is an absence of a common method of communication and that the methods preferred by individual clinicians, tend not to facilitate consumer involvement (e.g. verbal/ward rounds).

It is surprising that the theatre nurses within this survey are the most likely to prefer using informal methods (i.e. knowing doctors’ preferences and talking with the woman) as the main form of communication, because of the increased risk of adverse healthcare events occurring with this behaviour and the litigious environment that is associated with peri-operative care.

In the data triangulation, responses to this survey question from those at Site B are examined with the medical record audit findings to determine whether the tendency for discipline specific communication behaviours has any effect on the co-ordination and quality of patient care (Appendix G).

Site C’s Communicating ECS Care

The clinicians’ responses of always or frequently for each of the six communication statements from Site C are presented in Table 4.23.

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Verbal/ward rounds</th>
<th>Protocol guidelines</th>
<th>Medical record</th>
<th>Knowing individual Doctor</th>
<th>Talk with woman</th>
<th>Clinical pathway</th>
</tr>
</thead>
</table>
Table 4.23 shows that in total, the *routine* practice for determining what needs to be done next for an ECS consumer in Site C is talking with the woman (71%). This method is followed by accessing the medical record (68%) and verbal/ward rounds (64%). As discrete disciplines, the responses are spread across each of the communication methods in an ad hoc fashion. Doctors tend to favour talking with the woman and communicating via verbal/ward rounds, whereas nurse/midwives tend to favour the clinical pathway, followed by the medical record and verbal/ward rounds. Theatre nurses are more likely to include knowing the individual doctor’s preferences and talking with the woman as their methods of choice.

**Summary of Site C’s Communication of ECS Care**

The findings suggest that talking to the woman is the preferred option across all disciplines in Site C. The medical record is considered an appropriate tool when determining a consumer’s progress through the hospital continuum of care; however, the reliance on verbal methods of communication queries whether the medical record contents are representative of ECS care.

The clinicians’ individual preference for these communication methods suggests a lack of congruence in how they know what needs to be done next for a consumer, or organise ECS care. The findings support the likelihood of the consumer experiencing duplication, omission or variations of clinical care. An environment such as this is unlikely to foster consumer involvement and this speculation is further explored in the data triangulation (Appendix G).
Summary of Communicating ECS Care across the Three Sites

The primary intention of this section of the Clinician Domain is to identify the clinician’s preferred methods of communicating ECS care and also to determine if the medical record’s contents could be considered representative of the consumers’ progress through their healthcare continuum.

The findings indicate that the medical record is deemed to be an appropriate tool by the majority of the clinicians across the sites when seeking to communicate or find out what needs to be done next in ECS care. Although this finding is encouraging, with regard to the potential for the medical record to be representative of the consumer’s healthcare experience, the clinicians’ behaviours suggest that whilst clinicians may access (read) the record, they may not necessarily communicate (document) via the medical record.

Furthermore, the range of responses by clinicians throughout the survey makes it difficult to decipher what a standard method of communication is; that is, one that incorporates each clinical discipline’s preferred method of communication. The communication of ECS care is found to be discipline specific with minimal integration between disciplines and a preference for informal communication methods that preclude consumer involvement. The responses demonstrate the existence of professional sub-cultures in healthcare and a reliance on opportunistic communication methods rather than coordinated formal methods that are conducive to scrutiny and evaluation.

Summary of Domain Two – The Clinician

Domain Two - The Clinician examined the views of a sample of clinicians from each site who have been identified as documenting ECS care in the study’s medical record samples. The aim is to identify the clinicians’ perspectives about clinical practices and behaviours that could potentially facilitate the consumers’ participation in their healthcare. The clinicians’ self reported responses are the focal point of the Domain findings.
In consideration of the Domain’s objectives and to the study’s methodology, the key findings from Domain Two – The Clinician are summarised below so as to describe any relationships or differences that have emerged between and within the data sets.

The Clinician Domains’ demographic data demonstrates that each site’s clinician sample is proportionally representative of the mix of clinical disciplines that documented care in the medical record sample (p.173). The data highlights numerous similarities across the sites, such as similarities in the professional and employment status reported by each clinician sample. Significantly, cross-tabulation of the clinician data has been unremarkable, in that a relationship between the level of tertiary education, terms of employment, or the format or structure of clinical documents and the clinicians’ views and behaviours related to ECS care is unsubstantiated. Rather, the diverse range of reporting behaviours and views, both within disciplines and across sites, implies that any sense of responsibility to communicate healthcare, either with colleagues or the consumer, is dependent on the individual’s perception or motivation. This means that a relationship is emerging between the practice of individual clinicians being aligned with the contemporary consumer oriented model and an intrinsic drive to reflect on or communicate clinical practice, rather than any external influence.

Other noteworthy findings from each site’s data include:

- Site A’s clinicians are more likely to be aware of the existence of a document that organises and informs clinical care, and this is the only site whose documents have multidisciplinary representation
- Site B has not developed an information sheet; consequently, this site features an uncontested absence of standardisation or collaboration between disciplines or with the consumer
- Site C has numerous versions of clinical pathway documents and information sheets, which creates confusion rather than coordination of clinicians’ behaviours
In viewing this Domain’s findings as stand-alone data, the survey data cannot unequivocally confirm or deny the participative nature of individual clinician’s practices of including consumers in designing healthcare. As argued in the literature review, the clinician is only one dimension of the many facets associated with consumer participation in individual healthcare. The clinician survey findings do however demonstrate that the clinician does impact on consumer participation in healthcare by displaying a range of behaviours that limits collaboration between clinical disciplines, particularly in Site B and C. In explaining the tendency for the clinician to claim that talking to the woman is a preferred method of finding out what is to happen next in ECS care; it is likely that clinicians consult the woman because of an absence of any other systematised methods of communication, not because the woman’s input is required for designing care.

The findings indicate that the clinical disciplines practice healthcare within professional sub-cultures. The sub-cultures impact on the clinician’s behaviours particularly when organising clinical care and communicating what they do. The findings also suggest that clinicians tend to avoid systematic communication methods and regularly defer to traditional communication methods, such as meetings, ward rounds, and knowing preferences. The effects these behaviours are likely to have on the level of consumer participation activity are explored in the discussion in Chapter Five.

The findings from this survey of communicating care indicate that the majority of clinicians claim that the medical record is the preferred and most accessible source of evidence of the status and direction of the consumer’s healthcare experience. However, when reviewing this preference in the context of all the findings from this survey of clinicians, the data suggests that the clinicians may access the records for information but they do not necessarily communicate through the medical record. The inconsistent documenting behaviours reported by the clinicians, suggests that the medical record is a questionable resource, yet preferred source for clinicians’ decision making, planning or the evaluation of clinical care. The views and behaviours of the clinicians in this study implies that any potential absence of documentation
may not just be an *oversight* on their behalf, but indicative of the omission of the clinicians’ accountability to follow clinical protocols or meet their legal documenting obligations. These key findings will be further explored in Chapter Five’s discussion of the triangulated data. Findings from Domain Three – The Consumer will now be presented.
Domain Three - The Consumer

In this Domain, how the consumer interprets clinicians’ participative behaviours (i.e. information sharing, shared/inclusive decision making and coordination between clinical disciplines), and also how they perceive and rate their satisfaction with the level of participation experienced are the key areas of interest.

Building on the data from the Environment and Clinician Domain, which features an absence of coordination, consensus and consistency, it is apparent that the consumer sample is likely to encounter a diverse range of clinician behaviours during the ECS healthcare experience. However, the significance of the consumer survey for this study is to determine if there is a link between the individual consumer’s perception of the ECS experience and the evidence of consumer involvement in decision making in the medical record. For this reason, the individual consumer rating responses is examined with the medical record’s description of the ECS experience. This strategy is used to assist in understanding whether the contents of the medical records represent the consumers’ interpretations of the ECS experience.

Participative and Feedback Intentions of each Site

Before examining the consumers’ interpretations of participation in the ECS experience, each site’s data related to collaborative, participative and feedback strategies is revisited. Previously, the ‘Environment’ data (Tables 4.4, 4.5, & 4.6) has identified that each site’s capacity for collecting consumer feedback is ad hoc and lacking supportive infrastructure. The *Italic Font used in Table 4.24 denotes my comments (based on observation, interview and document audits).
Table 4.24 Summary of each site’s capacity for collecting consumer feedback

<table>
<thead>
<tr>
<th>Site A</th>
<th>Yes</th>
<th>Satisfaction survey distributed with postnatal package covers from outpatient to discharge. Likert satisfaction scale and open questions on service improvement. Pregnancy health record evaluation and working party reviewing findings. *Unsystematised process, limited feedback or impact from consumer survey, clinicians seek verbal consumer feedback.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site B</td>
<td>Yes</td>
<td>Patient Satisfaction Survey *Minimal knowledge of content, frequency of distribution, who was responsible and methods of feedback. (unit manager)</td>
</tr>
<tr>
<td>Site C</td>
<td>Yes</td>
<td>Recently ceased localised service evaluation in preference of an organisational wide approach co-ordinated by a private consultancy. *No feedback from evaluations to clinicians. Suggestion forms- distributed high profile/ volume locations. Form contained contact number for patient liaison service. *Accessing feedback from suggestions – unknown</td>
</tr>
</tbody>
</table>

In summary, Table 4.24 shows that across the sites, there is minimal evidence of formal opportunities for the consumer to provide feedback on how clinicians’ behaviours influence the ECS experience. Likewise, there is a scarcity of evidence about the level of consumer involvement or mechanisms that will direct consumer feedback to the relevant clinicians; therefore, consumers in the study sites are unlikely to impact on the design of clinical care or on the practice of individual clinicians. Furthermore, Domain One’s organisational and management orientation data (Table 4.13.1, 4.13.2 p.191) demonstrates that medical and cost related issues rather than consumer feedback mechanisms are likely to feature in each site. The management orientation data suggests consumer feedback issues are more likely to be addressed if they are in the context of complaints. Each of the site’s management orientation data indicates that quality review is a management rather than frontline clinician responsibility, whilst Site B’s data indicates no interest in consumer complaints unless related to an adverse event. The study’s data thus far supports asking the consumer their views on the ECS experience.
as the reporting and reviewing of clinical care at each site are ineffective in giving the consumer a voice in the ECS experience.

**Consumer Demographics**

In summary, the *contactable by mail* consumer response rate ranges from 69% to 92%, with an average response rate across the study being twenty-five consumers per site. The details of each site’s response rate and the difficulties experienced in contacting consumers in the sample are discussed in the Sampling Outcomes and can be found in Table 4.3 p.173.

Further analysis of each consumer’s demographic variables (parity, age, and financial category) is useful in confirming whether the consumers who respond are representative of each site’s medical record sample (Appendix E). As stated in Chapter Three, apart from confirming the representative nature of the sample, further analysis is not possible.

**Consumer Rating of Clinician Behaviours**

The intention of the retrospective consumer survey is to determine whether the consumers view the behaviours of the clinicians who care for them to be *participative*. Due to the retrospective nature of the survey, and the number and variety of clinicians who contribute to ECS care (Table 4.2 p.173), the consumer survey differentiates between care providers by referring to them as either doctors and nurse/midwives.

The consumers’ rating of the coordination of care between the professions is valuable in light of the communication behaviours in the Clinician Domain. The data here demonstrates that communication barriers are likely between the disciplines and that these barriers have the potential to influence the coordination of clinical care and ultimately the level of consumer participation.

As described in Chapter Three (pp.147-8), each consumer is provided with a five-point Likert scale (excellent, good, just acceptable, poor and don’t know)
for rating doctor and nurse/midwife behaviours. The sampling methods allow for the consumers' responses (N=56) to be examined for relationships and differences. This means that each site’s response table illustrates the consumer’s rating of clinician behaviours independently. The response tables also show the cumulative frequency for each response option by adding the total number of consumer responses for each of the behaviour ratings. This method of analysis provides a collective behaviour rating for each site, a rating that allows an inference as to the likelihood of the clinicians demonstrating the professional attributes of the consumer oriented model of healthcare (McMillan’s 2001; ATEAM 2001).

Site A’s Consumer Ratings of Clinician Behaviours

Site A’s consumer ratings of nurse/midwife and doctor information sharing and inclusive decision making behaviours are presented in Table 4.25. The cumulative total of those responses are totalled in order to describe the environment as perceived by the consumer. So when reading Table 4.25 from left to right, from the eighteen women who rated the survey question that asks about nurse/midwife (discipline) and information sharing about ECS care (behaviour), seven women gave an excellent rating, five a good rating, four just acceptable and two gave a poor rating.

Site A’s cumulative behaviour ratings are calculated in the last row. So when reading Table 4.25 from top to bottom, from a potential ninety responses, twenty-six responses are in the excellent clinician behaviour rating column. This cumulative total of the excellent rating column includes: nurse/midwives (7) and doctors (7) information sharing behaviours; nurse/midwives (5) and doctors (4) decision making behaviours; and, the coordination of care between doctors and nurse/midwives (3).
Table 4.25 Consumer Survey: Site A’s ratings of Clinician Behaviours

<table>
<thead>
<tr>
<th>Consumer (n=18) ratings of clinician behaviours</th>
<th>Excellent</th>
<th>Good</th>
<th>Just Acceptable</th>
<th>Poor</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse/Midwife Information sharing</td>
<td>7</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Doctors Information sharing</td>
<td>7</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nurse/Midwife Decision making</td>
<td>5</td>
<td>6</td>
<td>5</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Doctor Decision making</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Coordination of care between doctors and nurse/midwives</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Total Behaviour Rating (% of n=90)</td>
<td>26 (29%)</td>
<td>33 (37%)</td>
<td>18 (20%)</td>
<td>8 (9%)</td>
<td>5 (5%)</td>
</tr>
</tbody>
</table>

Table 4.25 shows that overall, eighteen consumers had ninety opportunities to rate clinician behaviours favourably. The consumer sample demonstrates a tendency to rate clinician behaviours favourably (excellent/good) fifty-nine times (66%); however, approximately one third of the sample (34%) rate clinician behaviours as just acceptable, poor or feel they can not rate the behaviour.

Individually, consumers have diverse views about clinicians’ information sharing and inclusive decision making behaviours. It is noteworthy that the inclusion of consumers in decision making by doctors and nurse/midwives is the behaviour that is most commonly rated as just acceptable.

At the boundaries of care (meaning healthcare that the consumer experiences between disciplines, rather than within a single discipline), coordination between doctors and nurses/midwives is the least favourably rated behaviour, with consumer ratings spread across the response range. This suggests that the consumer is aware of the communication barriers that exist between the clinical disciplines, which is similar to data in the previous Domain.

Framing Consumer Responses within the Medical Record Context

A further analysis of the consumer’s ratings involves a comparative analysis of each medical record’s evidence of information sharing, inclusion in decision making and coordination of care behaviours (Chapter Three pp. 152-3) as a
means to determine whether there is a relationship between the consumer’s ratings of clinicians’ behaviours and the events documented in the medical record. Disappointingly, yet not surprisingly, this method of analysis fails to make consistent links between how the women rate clinicians’ behaviours and their medical records’ documentation of events. However, the comparative review provides a valuable qualitative insight into the healthcare experience of each consumer. An example of this analysis follows.

Consumer One
Consumer one has given information sharing and inclusion in decision making behaviours by nurses/midwives a poor rating, and a don’t know rating for the same behaviours in doctors. This woman also gave a poor rating to the coordination of care between doctors and nurses/midwives.

A review of the consumer’s medical record indicates the sharing of clinical information (e.g. Hepatitis B vaccination and epidural information forms signed by consumer and clinician). Evidence of a request for an elective caesarean section, and a discussion of expected length of stay, preparation for birth and feeding preferences pre-operatively are also in the record. Post-operatively there is evidence of overt indicators of participation in infant feeding and discharge planning. This records’ documentation demonstrates that information sharing and decision making meets clinical and legal requirements. There is no obvious explanation for the ‘poor’ rating.

Further scrutiny of the contents within the record reveals a chain of events that could explain the consumer’s poor reflection of the clinician’s behaviours. It is stated in the record that pre-operatively this woman had a preference for breastfeeding and that she had formula fed her previous child. The post-operative notes record the woman’s nipples to be very tender; consequently, she requested a formula feed for her infant and her discharge plan was delayed to accommodate these feeding difficulties. After two more days of attempting to establish breastfeeding, the notes record that this woman decided to suppress lactation and formula feed her infant.
This sequence of events implies that the woman’s personal goal of establishing breastfeeding was not achieved, and that this woman may view that it is the role of the nurses/midwives to facilitate the attainment of breastfeeding skills. This could explain the rating of midwife behaviours as poor. Furthermore, this explanation also supports the don’t know or no opinion of the doctor’s behaviours because the doctor plays no role in this aspect of the healthcare experience, and is unlikely to influence breastfeeding outcomes.

This is just one example of Site A’s consumer ratings being compared with the medical record. In general, this method of analysis indicates an absence of evidence of a communication/feedback processes intended to assist consumers to clarify their expectations of involvement or provide opportunities to determine health outcomes that they value. In other words, clinicians provide and document competent care within the clinical sense of healthcare outcomes.

Summary Site A’s Consumer Survey Response for Clinician Behaviours

The survey data indicates that in 95% of cases, the consumer is able to express a view on clinician behaviours. The data supports the assumption that consumers have the capacity to rate their experience because they have their own expectations of the behaviours of health professionals to measure against. This finding is supportive of the practice of asking the opinion or views of the consumer, prior to their healthcare experience and then again after their experience.

Each consumer rates the behaviours of clinicians differently and they tend to be favourable in the rating. One third of the consumer sample rate clinician behaviours as just acceptable or less favourable, implying that clinician behaviours can still be improved. The indecision (responses ranging across the five options) by the consumer in rating the coordination of care between clinicians, suggests that communication barriers exist in the clinical setting; however, these barriers are not unsurmountable as the coordination is reported at times to be excellent.
Comparing the consumers’ views on clinician behaviour with their medical record provides an insight into what clinicians tend to document. The data indicates that evidence of *discussion* in the record does not consistently correlate with the consumer indicating a positive rating for clinician information sharing and decision-making behaviours. In other words, *discussed* may be a generalised term that clinicians use to reflect that information had been provided and a course of action consented to. However, the consumer might perceive *discussion* as being told or informed, not necessarily an inclusive process that invites involvement. This data will be considered in the study’s data triangulation and discussed in Chapter Five.

Site B’s Consumer Ratings of Clinician Behaviours

Site B’s consumer ratings of nurse/midwife and doctor behaviours are presented in Table 4.26. The frequencies for each response option are totalled individually and cumulatively, as explained in Site A’s data presentation.

<table>
<thead>
<tr>
<th>Consumer (n=17) ratings of clinician Behaviour(s)</th>
<th>Excellent</th>
<th>Good</th>
<th>Just Acceptable</th>
<th>Poor</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse/Midwife Information sharing</td>
<td>8</td>
<td>6</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Doctors Information sharing</td>
<td>9</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Nurse/Midwife Decision making</td>
<td>4</td>
<td>11</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Doctor Decision making</td>
<td>4</td>
<td>7</td>
<td>5</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Coordination of care between doctors and nurses/midwives</td>
<td>4</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total Behaviour Rating (% of n=85)</td>
<td>29</td>
<td>38</td>
<td>12</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 4.26 shows that overall, consumers had eighty-five opportunities to rate clinician behaviours favourably. The consumers rate clinician behaviours favourably (excellent/good) sixty-seven times (79%), while the remaining eighteen (22%) rate clinician behaviours as either just acceptable (14%), poor (4%) or don’t know (4%).
Similar to Site A’s data, each consumer has their own interpretation of Site B’s clinician information sharing and inclusive decision making behaviours. However, in contrast to Site A, Site B’s consumer sample rate information sharing by both the doctor and nurse/midwife favourably over 80% of the time. The inclusion of the consumer by the nurse/midwife in decision making is also viewed favourably by the consumer. It is noteworthy that the doctor’s inclusion of consumers in decision making is the least favourably rated behaviour and is rated as just acceptable by 30% of the consumers.

At the boundaries of care, coordination between doctors and nurses/midwives is rated favourably by 70% of the consumers.

Framing Consumer Responses within the Medical Record Context

Analysis of Site B’s consumer ratings by using a comparative review of the content in the consumer’s medical record is complicated, because attempts to track the consumer’s trajectory via the medical record is obstructed by the contents being fragmented and the preference by clinicians for objective medico-legal jargon to describe any interaction with the consumer. For example, one consumer from the sample (N=17) gave the information sharing and inclusive decision making behaviours of nurses/midwives a poor rating, whilst also rating coordination of care poor. A review of this woman’s medical record identifies minimal documentation by the nurse/midwife, which limits attempts to understand the consumer’s experience and subsequently her poor rating of clinician behaviours.

Another consumer from Site B gave a not applicable rating to the doctor’s inclusion of her in decision making. This woman’s medical record demonstrates comprehensive medical documentation of decision making and negotiation that is date/time/signed as taking place between the doctor and the woman. It is noteworthy, that the doctor’s confident and comprehensive documentation of decision making processes is a consistent feature of all Site B’s record samples, and yet this is the behaviour that is least likely to be reflected upon favourably by the consumers.
It is also apparent in the record review, that doctors prefer to transcribe their ‘discussions’ using objective medico-legal jargon, which means that the finer subjective nuances of information sharing and decision making are excluded from the record, or perhaps do not happen. It is also evident that Site B’s doctors commonly refer to the hierarchy within their discipline in order to confirm their decision making, and that a standardised method of documenting medical decisions in the record is used. This finding implies that medical hegemony as described by Crookes (1992) features within Site B’s approach to healthcare.

The comparative review shows that the favourable ratings given by the consumer, is not necessarily a reflection of an inclusion in decision making, rather it is an indication that the lack of inclusion is not unexpected. For example, the contents of the medical record in Site B suggests that, at least for the doctors, engaging consumers in decision making is a structured and directive process with the clinician determining the outcome. This directive approach is contradictory to the participative or collaborative attributes that the consumers’ favourable clinician behaviours ratings suggest. This paradox is an area of interest that is explored in the data triangulation and future discussions.

Summary Site B’s Consumer Survey Response for Clinician Behaviours

The survey’s data indicates that in 96% of cases consumers are able to express a view on clinician behaviours. This finding, similar to that in Site A, strongly supports the practice of asking the opinion or views of the consumer when being introduced to the healthcare service and once again after they have experienced that service.

Site B’s consumer responses to clinicians’ information sharing and inclusive decision making behaviours are diverse but generally positive. Using a one dimensional approach to this study, this data would support the assumption that a favourable rating by the consumer, indicates that the clinicians are competent in the attributes of a contemporary practitioner. However, with the benefit of the data from the Environment and Clinician Domains and a review
of the contents of the medical records, this assumption is contradicted by the
traditional paternalistic picture that has been a consistent feature of this site’s
data to date. This paradox supports the multifaceted approaches of this study
and will be discussed further in the data triangulation where I make sense of
the data acquired in this study.

At first sight, Site B’s favourable behaviour rating by the consumers suggests
that the level of involvement in decision making experienced by the women is
what they expected and that expectation is not for a partnership in decision
making. Hence, the consumer’s expectations are met and this is acknowledged
this with a favourable rating for clinician behaviours. This construct is further
explored through the data triangulation and discussed in Chapter Five.

Site C’s Consumer Ratings of Clinician Behaviours

Site C’s consumer ratings of the behaviours of the nurses/midwives and
doctors are presented in Table 4.27. The frequencies for each response option
are totalled individually and then cumulatively, as explained in Site A’s data
presentation.

Table 4.27 Consumer Survey: Site C’s rating of Clinician Behaviours

<table>
<thead>
<tr>
<th>Consumer (n=21) ratings of clinician Behaviour(s)</th>
<th>Excellent</th>
<th>Good</th>
<th>Just Acceptable</th>
<th>Poor</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse/Midwife Information sharing</td>
<td>11</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Doctors Information sharing</td>
<td>10</td>
<td>6</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Nurse/Midwife Decision making</td>
<td>10</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Doctor Decision making</td>
<td>8</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Coordination of care between doctors and nurse/midwives</td>
<td>7</td>
<td>9</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Total Behaviour Rating (% of n=105)</td>
<td>46 (44%)</td>
<td>42 (40%)</td>
<td>12 (11%)</td>
<td>2 (2%)</td>
<td>2 (2%)</td>
</tr>
</tbody>
</table>

Table 4.27 shows that overall, consumers had one hundred and five
opportunities to rate clinician behaviours favourably. The consumers rate
clinician behaviours favourably (Excellent/Good) eighty-four times (84%),
while the remaining behaviours are rated either just acceptable (11%), poor (2%) or don’t know (2%).

Replicating Site’s A and B, Site C’s consumer sample also interprets clinicians’ information sharing and inclusive decision making behaviours individually. In Site C however, the most favourable consumer ratings of both doctor and nurse/midwife behaviours are demonstrated. It is notable that doctors’ information sharing (19%) and inclusion of the consumer in decision making (14%) are the most likely to be rated as just acceptable by the consumer.

At the boundaries of care, coordination between doctors and nurse/midwives is rated favourably by 76% of the consumers. Though this is an encouraging rating, coordination of care is the least favourably rated behaviour along with doctors’ information sharing behaviours. This suggests a relationship between these ratings, in that if information is not being shared effectively the coordination of care may be adversely influenced.

Framing Consumer Responses Within the Medical Record Context

A comparative review of the contents of the medical record from Site C with the consumer survey data indicates similarities to Site B’s findings. For example, the consumers’ records are difficult to review due to the fragmentation of the clinicians’ documentation and the contents of the record being filed in a haphazard fashion. Furthermore, the contents clearly detail discussions of options and consumer requests for surgery by the doctors, whilst nurse/midwife contributions to healthcare are difficult to determine due to limited documented evidence of their interaction with the consumer.

The discussions doctors have with consumers tend to be approached and documented in a standardised, objective, medico-legal style. Unique to this site, the doctors routinely document a statement that implies that the woman requests, wants, wishes or prefers an elective caesarean section and also record supporting discussions (including statistics of various birthing options). Below is an example of this style of documentation:
35+4/40 – Breech confirmed on ultrasound, discussed ECV/ Vaginal Breech/ Elective Caesarean Section.

37/40 – patient not wishing ECV, discussed vaginal v’s caesarean birth – risks of both methods. Vaginal breech delivery discussed in detail including, advice epidural, possible elective episiotomy, forceps to baby’s head, possible risk of entrapment of head. Discussed risks and benefits of caesarean – offered elective caesarean section v’s leave until term – patient wants a vaginal breech delivery

38/40- Breech, patient would now prefer an elective caesarean section

Comparison between the survey data and each woman’s medical record is complicated (similar to that in Sites A and B) by an absence of nurse/midwife documentation that can support the consumers participative view of their behaviours, whilst the doctors comprehensive documentation of information sharing activities is viewed less than favourably by the consumers.

Summary Site C’s Consumer Survey Response for Clinician Behaviours

The data indicates that in 98% of cases, consumers are able to express a view on clinician behaviours. This finding, similar to those in Sites A and B, strongly supports the practice of asking the opinion or expectations of the consumer when planning or evaluating healthcare. Furthermore, an absence of evidence of the consumers’ views being comparable with the events documented in their medical record, suggests that the motive or practice of documenting consumer participation or their contribution to healthcare decision making/information sharing is not underpinned by a consumer-oriented philosophy, but rather a medico-legal strategy.

In Site C, the consumers report a mainly positive view of the information sharing and decision making behaviours of the clinicians and of the coordination of care. The survey data suggests that the clinicians demonstrate contemporary practitioner attributes and practice within a collaborative workplace. However, in reviewing the consumer rating with the contents of the medical record, these attributes are less obvious. Nurse/midwife documentation was conspicuous in its absence, whilst doctors tend to overtly detail the women’s
inclusion in consenting for the surgical procedure. This contradiction, similar to that in Site B, indicates that the ratings given to the clinician behaviours are not simply an expression of the woman’s current experience, but reflect the woman’s beliefs, values and prior experiences that now frame her expectations of the clinician and the level of involvement in her healthcare. These findings are discussed further in Chapter Five.

**Summary of Consumer Ratings of Clinicians Behaviours Across the Three Sites**

This section of Domain Three demonstrates that across three sites and 224 opportunities to rate behaviours and coordination of care, on only four (2%) occasions is the consumer unable to rate clinician behaviours and on only six (3%) occasions is the consumer unable to rate the coordination of care. This data highlights that consumers are capable and motivated to contribute to an evaluation of the organisation and provision of care in a clinical setting.

It is evident from this data that consumers tend to rate both doctor and nurse/midwife behaviours as good. Combining the sample of fifty-six consumers, information sharing behaviours (doctors 46% and nurses/midwives 46%) are more likely to be rated excellent than decision making behaviours (doctors 29% and nurse/midwife 34%). Individually, doctor’s decision making behaviours are the least favourably rated.

The data suggests that clinicians’ ability to share information with consumers is more developed than their ability to involve consumers in decision making. This finding is also supported by the Environment data in Domain One, where the clinicians report that consumer needs should be considered but their involvement is not necessary when clinical decisions are being made.

Examining the combined samples’ (N=56) response to coordination of care between doctors and nurse/midwives, seventeen (30%) consumers rate this behaviour as excellent, whilst nine (16%) rate just acceptable, four (7%) poor and six (10%) don’t know. The intention of this survey question is to discern the relevancy of McKenna’s (1995) ‘boundary of care’ theory (i.e. consumers tend
to report the boundary of care between clinical disciplines as a less favourable experience, than experience with an individual discipline). The data from this survey both supports and rejects McKenna's (1995) theory. In support, consumers are more likely to rate coordination between disciplines as poor in comparison to single discipline behaviours. In rejection of the theory, the least favourable rating across the sites is the decision making behaviours of doctors. In Site C, the data suggests a relationship between the unfavourable rating of doctors' information sharing and a similar unfavourable rating of coordination of care. In other words, ineffective behaviours of a single discipline is likely to adversely impact on the coordination of clinical care between multidiscipline groups and this adversity influences the consumers' experiences. This relationship will be further explored in the discussion in Chapter Five.

As stated previously, the significance of the consumer survey, for this study, is to determine if there is a link between the individual consumer's healthcare experience and the record of events documented in the medical record. In summary, this method of analysis has brought a number of relevant issues to the forefront.

Firstly, in Site A it is evident that clinicians are familiar with providing and documenting healthcare in the clinical sense. Secondly, in each of the sites, the evidence of discussion in the medical record tends to be a generalised statement, documented by clinicians to reflect routine information sharing that will justify consent for an intervention. On the other hand, the data also suggests that consumers view this approach to discussion as being told or informed, not an inclusive process that invites their involvement. Thirdly, there is a recurring absence of correlation between how each consumer rates clinician behaviours and the contents of their medical record. A positive or negative rating by the consumer is more likely linked to the level of involvement the consumer expected in decision making, rather than the evidence of inclusion in decision making or information sharing in the medical record.
In conclusion, the significant yet obvious finding from this section of Domain Three is that if one intends to facilitate consumers’ involvement or participation in their healthcare experience it is advisable to ask them what they expect from their healthcare experience (and from their clinicians) when they are being introduced to the service. Then ask the consumer whether their expectations were met at the conclusion of their healthcare experience. Of course this process needs to be contemporaneously documented in the medical record and then utilised by the service as evaluative evidence or a healthcare outcome measure.

The approach taken to collect and analyse the data from the consumer survey is considered valuable, in that the consumers have had the opportunity to present their unique views in respect to their healthcare encounter.

The following consumer survey questions extend the level of inquiry from rating clinician behaviours towards exploring the impact of these behaviours on the consumer. In particular, this section of the consumer survey asks if the women felt involved in healthcare decisions and whether she was satisfied with that involvement.

**Consumer Involvement and Satisfaction with Care Decisions**

In this section of Domain Three – The Consumer, the survey questions are designed with the purpose of providing a greater understanding or insight into the maternity care consumers’ feelings of involvement in healthcare decision making. Insight into the consumers’ satisfaction with her involvement, particularly when decisions are being made during the pregnancy, is also sought. Satisfaction with the involvement in healthcare decisions is examined, as the literature describes satisfaction as an outcome measure that reflects both a perceived positive experience but also a positive evaluation of that experience (Green 1999).

The survey offers the women a five-point satisfaction scale to rate how involved they felt in healthcare decision making. A response rating of *strongly agrees* has been highlighted in the literature to be an indicator of a positive
outcome measure or consumer satisfaction (Brown & Lumley 1994; Turnbull et al 1999a). It is of interest to this study to explore the consumer satisfaction ratings, because the literature also claims that consumers can feel satisfied with less than optimal care (Kaplan et al 1989a; NRCCPH 2002).

Aggregation of consumer survey responses has often been criticised as a limitation of the reliability of consumer satisfaction measures, for this reason individual consumer responses from each site are tabled.

Consumer Involvement and Satisfaction with Care Decisions in Site A

Table 4.28 Consumer Survey: Site A’s Decision Involvement/Satisfaction Responses

<table>
<thead>
<tr>
<th>Antenatal Care Statement responses</th>
<th>Strongly agree</th>
<th>Moderately agree</th>
<th>Undecided</th>
<th>Moderately disagree</th>
<th>Mostly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt fully involved in pregnancy care decisions (n=18)</td>
<td>10</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Fully satisfied with involvement in pregnancy care decisions (n=18)</td>
<td>10</td>
<td>7</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Site A’s survey data is presented in Table 4.28. Reading the table’s second row from left to right, eighteen women responded to the question that asks whether they felt fully involved in pregnancy care decisions. The women’s agreement with feelings of being fully involved in pregnancy care decisions include: ten strongly agreed; five moderately agreed; two were undecided; and, one moderately disagreed. Now reading the third row from left to right, eighteen women also indicate their feelings of satisfaction with the level of involvement they felt in pregnancy care decisions. Table 4.28 shows that, using strongly agree as the indicator of a positive outcome measure, from the eighteen women who responded, ten (55%) rate their involvement in pregnancy care decisions and/or satisfaction with their involvement, as positive. Only one woman moderately disagrees with being fully involved in pregnancy care decisions and no one disagrees with feeling fully satisfied with the level of decision involvement experienced.
To determine whether feeling fully involved in healthcare decision making is the prerequisite for consumer satisfaction (or a positive health outcome measure), each consumer response is examined independently. Four examples of the analysis of the data from the consumer survey are presented:

- One woman rates moderate disagreement with feeling fully involved in pregnancy care decisions and rates moderate agreement with feeling fully satisfied with this involvement.
- One woman is undecided about whether she feels fully involved and yet rates moderate agreement with being fully satisfied with the involvement.
- One woman rates full satisfaction (strongly agrees) with feeling moderately involved in pregnancy care decisions.
- One woman strongly agrees with feeling fully involved in decision making and rates moderate agreement with being satisfied with this full involvement.

Analysis of the survey’s involvement and satisfaction responses independently is an important exercise as it demonstrates that this sample may be satisfied with less than optimal involvement in care decisions (i.e. women report satisfaction with not feeling fully involved with pregnancy care decisions), and others in the sample are dissatisfied with feeling fully involved in healthcare decisions.

**Summary Site A’s Consumer Involvement/Satisfaction Data**

Site A’s data demonstrates that from the sample of eighteen consumers, using strongly agree as the positive satisfaction measure, ten are satisfied with their level of involvement in decision making. The data also implies that full involvement in decision making does not consistently rate with a positive consumer satisfaction measure, and a lack of involvement in decision making does not correlate with a less favourable satisfaction measure.

The data demonstrates that satisfaction is a self-assessment outcome measure, and measuring consumer satisfaction requires clarification as to what criteria the consumer is basing this measure on. In other words, the value that the
consumer places on her involvement in healthcare decisions must be taken into consideration when interpreting the consumer’s satisfaction rating. This is a significant finding that will be further discussed in Chapter Five.

Consumer Involvement and Satisfaction with Care Decisions in Site B

Site B’s seventeen consumer response ratings is examined for the level of involvement in healthcare decisions and the level of satisfaction felt as a result of this involvement. Site B’s survey data is presented in Table 4.29.

Table 4.29 Consumer Survey: Site B’s Decision Involvement/Satisfaction Responses

<table>
<thead>
<tr>
<th>Antenatal Care Statements</th>
<th>Strongly agree</th>
<th>Moderately agree</th>
<th>Undecided</th>
<th>Moderately disagree</th>
<th>Mostly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt fully involved in pregnancy care decisions</td>
<td>11</td>
<td>6</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Fully satisfied with involvement in pregnancy care decisions</td>
<td>10</td>
<td>7</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 4.29 shows that from Site B’s seventeen consumers, eleven (65%) rate their involvement in pregnancy care decisions, and ten (59%) their satisfaction with involvement, as strongly positive. The remaining consumers rate their satisfaction as favourable, and none of them disagree that they feel involved in pregnancy care decisions.

An individual examination of the consumer data identifies that a comparison of involvement and satisfaction ratings are unremarkable except for one consumer who considers herself fully involved in pregnancy care decisions yet only moderately satisfied with this involvement. These findings suggest a stronger association between involvement and satisfaction than those in Site A.

Summary Site B’s Consumer Involvement/Satisfaction Data

Site B’s data demonstrates that from the sample of seventeen consumers, using strongly agree as the positive outcome measure, ten rate their level of involvement in decision making as satisfying. Furthermore, the aggregated data indicates that the consumers believe their inclusion in decision making is
positive, with no-one giving a negative rating. Apart from one consumer’s response indicating otherwise, the data suggests that the level of involvement in decision involvement felt by the consumers, reflects their expectations of involvement and that they are mainly satisfied with that involvement.

This data has implications of significance that will be examined in the context of this study’s four Domains, and will be discussed in Chapter Five.

Consumer Involvement and Satisfaction with Care Decisions in Site C

Site C’s twenty consumer responses are presented in Table 4.30, the data is examined for how each woman felt about her involvement in healthcare decisions and the level of satisfaction associated with this involvement.

Table 4.30 Consumer Survey: Site C’s Decision Involvement/Satisfaction Responses

<table>
<thead>
<tr>
<th>Antenatal Care Statements</th>
<th>Strongly agree</th>
<th>Moderately agree</th>
<th>Undecided</th>
<th>Moderately disagree</th>
<th>Mostly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt fully involved in pregnancy care decisions</td>
<td>13</td>
<td>5</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Fully satisfied with involvement in pregnancy care decisions</td>
<td>13</td>
<td>6</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 4.30 shows that, using strongly agree as the indicator of a positive outcome measure, from the twenty women who respond, thirteen (65%) rate their involvement in pregnancy care decisions and satisfaction with her involvement, as being positive. One woman strongly disagrees with being fully involved in pregnancy care decisions and no-one disagrees with feeling satisfied with the level of involvement experienced.

Examples of the individual examination of the consumer data include:

- One woman rates mostly disagree with feeling fully involved in pregnancy care decisions and rates strongly agrees with feeling satisfied with the lack of involvement

- One woman is undecided as to whether she feels fully involved in pregnancy care decisions, yet rates moderately agrees when considering her satisfaction with that involvement
One woman rates moderately agrees with feeling fully involved in pregnancy care decisions, yet is undecided as to whether she is satisfied with that involvement.

One woman strongly agrees that she is fully involved in decision making, yet moderately agrees that she is satisfied with this full involvement.

Similar to that of Site A, Site C’s data supports that if the intention is to interpret consumer satisfaction with their healthcare experience, the value the consumer places on involvement in healthcare decisions must be considered.

Summary Site C’s Consumer Involvement/Satisfaction Data

Site C’s data demonstrates that from the sample of twenty consumers, using strongly agree as the positive satisfaction measure, thirteen claim to be satisfied with how involved they are in healthcare decision making. The data supports the suggestion that full involvement in decision making would not always result in a positive satisfaction measure by consumers. Furthermore, a lack of involvement by the consumer in decision making does not necessarily correlate with a less favourable satisfaction measure. This data will be considered in the study’s data triangulation.

Summary of Consumer Involvement and Satisfaction with Care Decisions across the Three Sites

The study findings so far, have yet to support the rhetoric that involvement in decision making between consumers and clinicians is now usual practice in the antenatal or pre-admission period, of an elective surgical procedure. This section’s survey questions examine how the consumer feels about their involvement in pregnancy care decisions and their feelings of satisfaction with that involvement.

The data indicates that across the three sites, between 55% and 65% of consumers strongly agree, and therefore feel satisfied with their full involvement in pregnancy care decisions. In other words, 35% to 45% of the consumer sample is dissatisfied with their involvement in the decision making. Site A’s consumers, in comparison to Site B and C’s consumers are the least satisfied.
with their involvement in pregnancy care decisions. This finding contradicts the propensity for consumer involvement identified in the Environmental Domain of the study (p.178) and is explored further in the data triangulation chapter.

To assess whether a positive outcome measure by the consumer is linked to full involvement in decision making, each consumer’s response has been examined independently. This method of analysis indicates that some consumers feel satisfied with less than full involvement in decision making and in contrast, those who feel fully involved, are not always satisfied with the level of involvement. The data supports the argument that reviewing consumer responses individually provides a clearer perspective on each consumer’s interpretation of their experiences, than aggregated analysis does. Furthermore, the inference that a generic consumer satisfaction measure could actually be capable of representing the quality of the consumer’s healthcare experience is questioned. These significant findings will be revisited in the discussion chapter.

**Summary of Domain Three – The Consumer**

The intentions of Domain Three - The Consumer are to ask the consumers about the participative behaviours of clinicians and how involved they felt in healthcare decision making. This information is sought directly from the consumer, as the data from the Environment Domain indicates that each site’s existing consumer feedback/evaluation methods are unlikely to provide this detail. Furthermore, the data from the Clinician Domain suggests that consumers are likely to have experienced a variety of clinician behaviours and hence the consumers’ own evaluation of their participation or involvement in their healthcare experience is invaluable data.

The methods employed in this domain have met the stated intentions. The demographic data of the fifty-six consumers that completed the survey across the three sites shows that each of the demographic variables (e.g. parity, age, and financial category) is represented in each site’s medical record sample.
Apart from demonstrating the representativeness of the sample, further analysis is not possible.

The response patterns that emerge from data of the consumer survey indicate that consumers have individual expectations of clinicians and clinical disciplines. The consumers are capable of: expressing an opinion of their experience of clinician behaviours; differentiate between their expectations of different clinical disciplines; provide an interpretation of how their care is coordinated by clinicians; and finally, are able to provide an evaluation or outcome measure of how involved they felt in pregnancy care decisions.

The data allows a number of assumptions to be explored. For example, overall, consumers tend to rate clinicians’ behaviours favourably. However, clinicians are viewed as having a greater ability to share information with consumers than to involve them in decision making. The data supports the clinician’s own acknowledgement (i.e. Environment Domain data) that consumer needs should be considered, but their involvement is not necessary when clinical decisions are being made.

The frequency of poor ratings in relation to the coordination of care between doctors and nurses/midwives supports McKenna’s (1995) prediction that consumers are likely to view this behaviour less favourably in comparison to behaviours within single disciplines. However, the fact that doctors’ decision making behaviours is given overall the least favourable rating and that the unfavourable rating for doctors’ information sharing is associated with an unfavourable rating for coordination of care, supports the value of continuing to examine single discipline behaviours as a method of identifying the underlying issues that adversely influence the coordination of clinical care between disciplines.

Comparing the consumers’ rating of clinician behaviours with the evidence of information sharing and inclusion in decision making in their medical record, highlights the point that clinicians tend to detail the outcomes and actions of clinical care decisions rather than the preceding processes. Discussion or
versions of this word, emerge as representing the clinicians’ standard approach to information giving and gaining consent for interventions. However, the consumer does not necessarily view this approach to be inclusive or inviting of their involvement.

I consider the most significant finding from the analysis of the data is that a favourable or unfavourable rating by consumers cannot be consistently verified through documented evidence of any inclusion in decision making or information sharing. The data indicates that each consumer has a different view on the behaviours they expect from clinicians, and despite the lack of evidence or overt evidence of participative behaviours documented in the record, without asking each consumer what their expectations are, one cannot make any further analysis of the findings.

The next bank of survey questions asked the consumer about their feelings of involvement in decision making and how satisfied they are with that involvement. This self assessment is an important exercise that is supportive of earlier findings that show that the consumers’ views cannot be generalised as being representative of a similar measure, meaning that consumer satisfaction does not necessarily correlate with their level of involvement in decision making. For example, 35% to 45% of the consumers in the study do not feel their involvement in decision making to be satisfying; however, the same consumers may feel fully involved in decision making.

The data questions the inference that a generic consumer satisfaction measure, or any aggregated measure, can reliably represent the quality or the multifaceted features of the consumer’s healthcare experience, without first asking or clarifying each consumer’s expectations of that healthcare experience.

In closing, the data suggests that although consumers are predominantly favourable in their views and evaluations of their healthcare experiences, their responses and their medical records do not support that a partnership exists. The suggestion that sharing and involvement are components of clinician
behaviours is questionable. Furthermore, consumer satisfaction being dependent on being a partner in the healthcare experience is also questionable. The data suggests that the consumers and the clinicians are functioning on parallel levels, with minimal ability or capacity (from either party) to clarify their expectations of each other in the healthcare experience. The significant findings detailed in this chapter, will each be discussed in further detail, both independently and within the context of the triangulated data in Chapter Five.
Domain Four - The Medical Record

The reason for exploring the medical record in this Domain is to examine the content and completeness of each site’s record samples. The contents are used to determine the level of consumer participation activity in information sharing and decision making throughout the healthcare continuum. The medical record has been chosen to be the evidence source for this Domain because of its reputation as the solitary defendable link between all factors and persons related to an individual’s healthcare experience (Wolf 1985).

The Medical Record Contents Audit

This section aims to examine the contents of each site’s medical record sample, using a structured audit tool (Appendix C), for documented indicators of consumer participation. The audit tool is comprehensively detailed in Chapter Three (pp.159-61).

The method involves a retrospective audit of each medical record (that fulfils the study’s rigorous sampling procedure pp.116-7) from the three sites through the hospital care continuum: commencing with the pre-operative (antenatal clinic/preadmission clinic/admission) episode; progressing to the post-operative (post-partum) episode; and, concluding with the hospital discharge episode. Documentation within the hospital medical record is the sole determinant for indicators of partnership between clinicians and consumers in information sharing, decision making and evaluating healthcare.

The intention is to classify the presence or absence of documentation, which indicates consumer/clinician partnership. Observations or actions recorded in the medical record, which indicate an inclusion of the consumer in decision-making and/or information sharing relating to determining healthcare needs are classified.

As detailed (p.159), a validated coding criterion or professional consensus on indicators of consumer participation was unable to be confirmed prior to the study. Hence, an audit tool has been designed to allow the recorded
observations to be systematically classified into three broad categories (Appendix C). Documentation is categorised as either:

- **Overt** – represents predominantly obvious inclusion of the consumer, including care planning requests and evaluative feedback from the consumer

- **Implied** – represents that there is an absence of consumer inclusion yet there is some suggestion of consumer inclusion, but it is not obvious

- **Absent** – represents no documented evidence of inclusion of the consumer

To accommodate for variable documentation practices in the medical record and to ensure any legible indicator of consumer participation is included, a very liberal approach has been taken when identifying and classifying the documentation.

The consumer participation indicator audit is central to determining the study’s objectives. For this reason the participation indicator audit will be detailed for each site, followed by the medical record’s completeness audit. The chapter concludes with a comparison and summary of the Medical Record Domain’s key findings.

**Site A’s Medical Record Audit Findings**

The rigorous sampling process and inclusion criterion that has been used to define the record samples originates from the Commonwealth project and is detailed in Chapter Three (pp.116-7). It is my responsibility (both for this study and as a member of the Commonwealth project team) to review each site’s record sample to ensure they meet the sampling criterion. A record is only excluded from the sample after consultation and agreement between at least two project team members. From the fifty medical records made available in Site A for the study, nine records have been excluded, leaving forty-one records to be audited. Each of the forty-one records has undergone the same structured retrospective audit.
Site A’s Medical Record Demographic Data

This data describes the demographic variables taken from the record. The demographic variables provide broad background details and are useful in determining the representativeness of Site A’s consumer survey sample (Domain Three). Site A’s data will be compared with Site B and C’s demographics in the data triangulation. As discussed, the sample size does not allow for any further meaningful analysis of the variables.

Site A’s consumer demographic variables (age, parity, financial category and clinical indicator) have been grouped into response ranges. The variables are then tabulated according to the modal frequency and percentage of modal frequency (Table 4.31). For example, the fourth demographic variable is clinical indicator; this data has been split into two categories, first birth and subsequent birth. In examining the ‘first birth’ (range of variable) the clinical indicator most likely to be recorded is a breech presentation. This indicator is evident in six of the nine records (modal frequency) or 67% of the record sample (% of modal frequency) in the first birth range.

Table 4.31 Medical Record Audit: Site A’s Consumer Demographic Variables

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Range of Variable</th>
<th>Modal Frequency</th>
<th>% Modal Frequency of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Age</td>
<td>22 – 42 yrs</td>
<td>25 – 34 yrs (22/41)</td>
<td>54%</td>
</tr>
<tr>
<td>Birth Experience</td>
<td>First – Fourth Birth</td>
<td>Second Birth (20/41)</td>
<td>49%</td>
</tr>
<tr>
<td>Financial Category</td>
<td>Public - Private</td>
<td>Public (29/41)</td>
<td>71%</td>
</tr>
<tr>
<td>Clinical Indicator</td>
<td>First Birth</td>
<td>Breech presentation (6/9)</td>
<td>67%</td>
</tr>
<tr>
<td></td>
<td>Subsequent Birth</td>
<td>Previous C/S (28/32)</td>
<td>87%</td>
</tr>
</tbody>
</table>

Table 4.31 shows that the maternal age of the sample is a twenty year span, with a predominant age grouping of 25 – 34 years. Birth experience ranges from first birth to fourth birth. Women experiencing their second birth represent nearly half of the sample population (49%). The financial category variable shows a tendency for the women to be admitted under the public, non-chargeable (71%) rather than private, chargeable (29%) category. The most common clinical indicator for an elective caesarean section, for a woman experiencing her
first birth, is a breech presentation and for a woman experiencing a subsequent birth, is a previous caesarean section.

The demographic variables alone do not provide an indication of the level of consumer participation experienced by the sample. However, the demographic variables provide a broad background of the population for Site A’s record samples.

Site A’s Indicators of Consumer Participation

In this section, the outcomes of the classification of the record audit (n= 41) for documented indicators of consumer involvement in information sharing and decision making, into the pre-admission/operative, post-operative and discharge episodes of healthcare are presented. The records are classified into the indicator category that reflects the documentation for that episode of care (i.e. either overt, implied, or absent). Only one category is allocated per episode, per record. Records that demonstrate a mix of indicators (e.g. implied and absent indicators) in the same healthcare episode have been classified into the most dominant indicator category.

After the records have been classified, the data is tabulated (Table 4.32). For example, reading Table 4.32, Site A’s Pre-operative Episode from left to right: two records are classified as absent of indicators; five are classified in the implied indicator category; and thirty-four are classified in the overt indicator category of consumer participation. This process has been repeated for both the post-operative and discharge episodes, resulting in one hundred and twenty three episodes of care being classified across the sample of forty-one records.

<table>
<thead>
<tr>
<th>Episode</th>
<th>Absent</th>
<th>Implied</th>
<th>Overt</th>
<th>Total Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Operative</td>
<td>2</td>
<td>5</td>
<td>34</td>
<td>41</td>
</tr>
<tr>
<td>Post-Operative</td>
<td>30</td>
<td>0</td>
<td>11</td>
<td>41</td>
</tr>
<tr>
<td>Discharge</td>
<td>31</td>
<td>4</td>
<td>6</td>
<td>41</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>63</strong></td>
<td><strong>9</strong></td>
<td><strong>51</strong></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.32 shows that out of 123 episodes in the healthcare continuum to potentially document consumer participation within the record, either implied or overt, there is evidence of this in less than half (60/123) of the care episodes. It also highlights that in the remaining (63/123) healthcare episodes, there is an absence of evidence of indicators documented.

When the records are separated into the continuum of care, the pre-operative episode stands out as the most comprehensive in relation to the presence of either overt or implied indicators; for example 39/41 (95%) of the records contain evidence of consumer participation. In comparison, the post-operative and discharge episodes are more obvious for their lack of consumer participation indicators, with only eleven and ten episodes respectively being classified as indicating any inclusion of the consumer participating in information sharing and decision making.

Interpretation of Consumer Participation Indicators

Out of 123 episodes across the continuum of care, there are only sixty episodes where documented indicators are present that communicate or suggest any form of consumer participation. In other words, in over half of the care episodes there is no indication of information sharing or the consumer being included in healthcare decisions, either by simply marking or signing a box designed to guide the clinician’s practice.

As previously stated, I have been very liberal when classifying each record’s documentation. Some examples of overt and implied participation indicators are listed below:

**Overt Indicators** –

‘Patient wishes to discuss options, Nicole is concerned her pelvis is too small’ (Pre-operative documents)

‘Happy for baby to have formula, will express tomorrow after IV therapy and catheter are out’ (Post-operative documents)

‘Patient would like to go home Friday’ (Discharge document)
Implied Indicators -

Pre-anaesthetic questionnaire completed by consumer (Pre-operative documents)

‘Melissa teary re ultrasound, education and support provided’ (Pre-operative document)

‘Discharged home, referral completed – check for depression’ (discharge document)

As shown in Table 4.32, evidence of overt indicators of consumer participation is more likely (34/41 or 83%) to occur during the pre-admission/operative episode than the post-operative (11/41 or 27%) or discharge (6/41 or 15%) episodes of care. The data suggests that either the clinician is more likely to be attentive to documenting the participative components of their practice in the pre-admission/operative episode of the healthcare continuum or perhaps consumers tend to be more inquisitive or demanding during this episode, compared to after surgery.

Site A’s Consumer Participation Themes

I have repeatedly stated that any conjecture made in relation to the study’s data is limited to the documentation present, rather than absent, in the records. Therefore, to meaningfully understand the relevance of the data, further exploration of the documentation that is present (implied or overt indicators) is needed. It is of interest to this study, that in completing the audit, it has become obvious that clinicians’ documentation of any interaction or involvement with consumers in clinical care tends to be written in either a structured and predictable style or an unstructured and random style. As a clinician myself, I am aware that clinicians do tend to practice minimalism when documenting. However, for the purposes of this study, this means that the clinician’s sentence structure is likely to be disjointed and/or devoid of descriptive adjectives. Therefore, to make sense of the level of participation activity that each record’s documentation implies, Site A’s audit data has been revisited, using the guidelines outlined in Chapter Three (p.161).
This means that the sequences of documentation that have been classified as either *overt* or *implied* are now regrouped using common words into themes related to information sharing and healthcare decision making. Of the 41 records audited, 144 sequences of documentation are classified into ten broad themes (Table 4.33). These themes originate from the documentation audit because a validated coding criterion or professional consensus on what can be considered an indicator or theme of consumer participation is not available.

As evidence of consumer participation is more likely in the pre-admission/operative episode of care (Table 4.32), it is not surprising that the consumer participation themes are more likely to be associated with the pre-admission/operative episode. For example in Table 4.33, from Site A’s sample of 41 medical records, 27 records include *overt* or implied *sequences* of documentation related to the consumer participation theme of *maternal request for caesarean section*.

**Table 4.33 Site A’s Consumer Participation Themes**

<table>
<thead>
<tr>
<th>Overt/Implied Consumer participation indicator themes identified in medical record sample (n=41)</th>
<th>Number of medical records with indicator themes evident in contents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal request for caesarean section</td>
<td>27</td>
</tr>
<tr>
<td>VBAC discussed</td>
<td>9</td>
</tr>
<tr>
<td>Feeding preferences discussed</td>
<td>26</td>
</tr>
<tr>
<td>Breech options discussed</td>
<td>6</td>
</tr>
<tr>
<td>ECV attempted</td>
<td>2</td>
</tr>
<tr>
<td>Tubal ligation discussed</td>
<td>5</td>
</tr>
<tr>
<td>Discharge plan discussed</td>
<td>29</td>
</tr>
<tr>
<td>Antenatal screening discussed</td>
<td>2</td>
</tr>
<tr>
<td>Anaesthetic discussed</td>
<td>12</td>
</tr>
<tr>
<td><strong>Specific consumer requests</strong></td>
<td>20</td>
</tr>
</tbody>
</table>
** Specific requests – is a collation of individual consumer initiated specific requests that were documented by clinicians including: Surgery technique request, Patient request, Referral request, Fears/anxiety/concerns discussed

Table 4.33 shows that clinicians have a preference for recording three aspects of care: request for caesarean section; feeding preference discussed; discharge plan discussed. The repeated documentation of these aspects of care across Site A’s record sample, suggests that the clinician and/or consumer discusses and most importantly documents the outcomes of discussions related to these aspects of care. This implies that there is potential for consumer/clinician partnership in healthcare planning. However, this sense of partnership is not as prevalent in the remaining episodes of healthcare. For example, some obvious indicators of participation, such as discharge planning have been clearly documented in the pre-operative episode, yet when tracked through the consumer’s medical record it is noted that the discharge plan is not referred to, nor is it the basis for planning the consumer’s discharge. An example from Site A’s record sample shows this:

Pre-operative documentation states, that the woman’s expectation of a repeat caesarean section and planned length of stay to be three days.

Day 2 post-operative documentation states, ‘the patient wishes to go home tomorrow’. Day 3 - discharge delayed as the process of, arranging medical review and follow-up, fails to be commenced till late on evening of Day 2.

Reading the record of events documented above, I would argue that it is reasonable for the consumer to assume that after formally participating in discharge planning activities (documented in pre-admission notes) that the request to go home on Day 3 would be anticipated and planned for. However, it appears that discharge planning means filling-in the designated space on the admission sheet. More significantly, if this is the case, the overt or implied evidence of involvement in care planning (e.g. discharge planning discussed) identified in the pre-admission/operative documents, is not representative of the practice of consumer participation but a token gesture. This finding supports the evidence of consumers being less than satisfied with feeling fully
involved in healthcare decisions (Domain Three data). These findings are explored further in the data triangulation chapter (Chapter Five).

The listing of consumer participation themes (Table 4.33) highlights a correlation between the format of clinical documents and the presence of participation themes in the medical records. Furthermore, the consumer participation themes indicate that the documents have been formatted to engage the consumer in planning aspects of care that are safe; this means that the consumer is manipulated via the format of the document to limit involvement to token aspects of healthcare partnership. For example, clinicians are twice as likely to document consumer participation in the discussion of infant feeding preferences (26/41 or 63%), compared with discussions related to anaesthetic issues (12/41 or 29%). In other words, consumers’ feeding preferences are unlikely to disrupt the organisation of care, by comparison, the discussion of anaesthetics has a number of implications. For example, an anaesthetist has to be accessible to the doctor or nurse/midwife, and after providing information the consumer might request a service or technique that the anaesthetist does not provide, which may disrupt the theatre list etc. This interpretation of the data suggests an asymmetry of involvement rather than partnership.

The absence of evidence of any indication of consumer participation (Table 4.32) in over half the potential opportunities to record information sharing and inclusion in decision making also suggests asymmetry. In other words, consumer participation is an optional practice or only offered if the clinician considers it relevant (e.g. to complete forms etc). The findings also raise the question about whether the absence of documented indicators reflects a non-participative healthcare encounter between the clinician and the consumer, or an incomplete or censored record of events.

**Summary of Site A’s Consumer Participation Indicators**

The evidence and the absence of evidence, of consumer participation documented in Site A’s record sample is approximately equal. Across the healthcare continuum, clinicians are more likely to make use of participative documentation in the pre-admission/operative episodes, than in the post-
operative or discharge episodes. Evidence of participation indicators tends to be associated with the format of the document or the inclination of the individual clinician.

The tendency of clinicians to practice minimalism when documenting healthcare, limits attempts to determine the level of activity implied by the participative documentation. However, when examining the content or themes that the participation indicators refer to, an asymmetry of involvement is revealed. Asymmetry means that the documented consumer participation indicators are clinician-led or environment-led, so that consumer involvement is not a partnership and is unlikely to impact on health outcome measures.

The data demonstrates that there is a propensity for participation in the pre-admission/operative episode of care, yet this level of participation activity is not sustained through the healthcare continuum, which suggests a fragility in Site A’s consumer participation activities. The absence of evidence of consumer participation indicators in over half of the sample is another significant trend and has been linked to a multitude of possibilities. It is argued as being representative of: a lack of consumer involvement in healthcare; an absence, or poor quality of clinician documentation; or a reflection of the data collection methods. These issues are examined in further detail, and a comparison is made with the completeness audit, in the following data triangulation chapter.

**Site B’s Medical Record Audit Findings**

The initial sample of fifty medical records have been through the same rigorous sampling and exclusion processes as Site A, prior to being included in Site B’s final record sample. Eleven records were excluded from the study, leaving thirty-nine to be audited for the purposes of the Commonwealth project and this study. Each of the thirty-nine records have been through the same structured audits that have been detailed in Site A’s medical record audit findings and in Chapter Three. To minimise repetition, each method of data analysis is introduced briefly and then expanded upon if the findings are unique to Site B.
Site B’s Medical Record Demographic Data

The consumer demographic variables identified in Site B’s record sample have been collated and grouped into a range of variables. The demographic data is tabled according to modal frequency and percentage of modal frequency (Table 4.34). The sample size prevents any further detailed analysis of the variables.

Table 4.34 Medical Record Audit: Site B’s Consumer Demographic Variables

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Range of Variable</th>
<th>Modal Frequency</th>
<th>% Modal Frequency of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Age</td>
<td>19 – 41 yrs</td>
<td>25 – 34yrs (25/39)</td>
<td>64%</td>
</tr>
<tr>
<td>Birth Experience</td>
<td>First – Sixth Birth</td>
<td>Third Birth (12/39)</td>
<td>31%</td>
</tr>
<tr>
<td>Financial Category</td>
<td>Public - Private</td>
<td>Public (39/39)</td>
<td>100%</td>
</tr>
<tr>
<td>Clinical Indicator</td>
<td>First Birth</td>
<td>Breech presentation (3/5)</td>
<td>60%</td>
</tr>
<tr>
<td></td>
<td>Subsequent Birth</td>
<td>Previous C/S (28/34)</td>
<td>82%</td>
</tr>
</tbody>
</table>

Table 4.34 shows that Site B’s record sample’s financial category is exclusively public (i.e. non-chargeable healthcare consumers). The sample’s age range is within the Australian childbearing population statistics, and the women in this sample are more likely to have experienced childbirth before and that experience is likely to have been a caesarean section.

True to the intentions of this analysis, the demographic variables provide a broad demographic background of the population, for Site B’s record sample. The demographic data is useful when determining the representativeness of Site B’s consumer sample and will be compared with samples from Sites A and C in the following data triangulation chapter.

Site B’s Indicators of Consumer Participation

The record audit systematically tracks Site B’s thirty-nine consumers through their healthcare continuum, looking for evidence of consumer involvement in information sharing and decision making. The audit approach is progressive, following the consumer through pre-admission/operative, post-operative and discharge episodes, and classifying each episode into the dominant
participation indicator category evident in each record. In other words, for each record, each episode of the continuum is allocated one indicator classification (Table 4.35). From the sample of thirty-nine records, one hundred and seventeen episodes of care have been audited.

Table 4.35 Medical Record Audit: Evidence of Consumer Participation Indicators in Site B

<table>
<thead>
<tr>
<th>Episodes</th>
<th>Absent</th>
<th>Implied</th>
<th>Overt</th>
<th>Total Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Operative</td>
<td>4</td>
<td>3</td>
<td>32</td>
<td>39</td>
</tr>
<tr>
<td>Post-Operative</td>
<td>39</td>
<td>-</td>
<td>-</td>
<td>39</td>
</tr>
<tr>
<td>Discharge</td>
<td>36</td>
<td>-</td>
<td>3</td>
<td>39</td>
</tr>
<tr>
<td>Total</td>
<td>79</td>
<td>3</td>
<td>35</td>
<td></td>
</tr>
</tbody>
</table>

Table 4.35 shows that out of the 117 opportunities to document consumer participation across the sample of records, there is evidence documented in about one third (38/117) of the episodes of care. This means that in two thirds (79/117) of the care episodes, evidence of the documentation of participation indicators is absent.

In examining the evidence of indicators in the discrete episodes of care, the pre-admission/operative episode of care is most likely to include the presence of either overt or implied indicators with 34/39 (90%) of the records indicating evidence of consumer participation. In comparison, the post-operative and discharge episodes are more notable for their lack of consumer participation indicators with, 0/39 and 3/39 respectively indicating any presence of consumer participation.

Interpretation of Consumer Participation Indicators

With potentially 117 episodes of care to either communicate or suggest any form of consumer participation across the healthcare continuum, participation indicators are evident in just thirty-eight episodes, with thirty-four of those being in the pre-admission/operative episode of care. The data indicates that either the medical record audit is an inadequate measure of consumer participation or that consumers are unlikely, apart from during their pre-
admission/operative episode, to participate in information sharing or decision making during the healthcare experience.

As stated previously, a liberal approach has been taken when identifying and classifying consumer participation indicators. Examples of overt participation indicators for Site B include:

“Wants elective caesarean, risks explained but she still wants caesarean section – Theatre booked (Doctor)

“Nil investigations wanted in this pregnancy” (Doctor)

“Patient keen for discharge, offered to stay but keen to go, does not want Rubella vaccine” (Midwife)

The three episodes of implied indicators in the pre-admission/operative episode have the words requests caesarean section documented. However, there is an absence of evidence to support that these words are the outcome of a participative process; therefore, the words are only considered suggestive of consumer participation.

To understand what the data means, further exploration of the documentation is warranted. A finding significant to Site B is that the contents of the medical record are dominated by entries made by medical clinicians. In particular, medical documentation is prominent during the pre-operative period, with a significant amount of documentation describing discussion, options and decisions for proceeding with an elective caesarean section. For example:

“Twenty weeks pregnant - Interested in elective caesarean section, previous emergency caesarean section for cephalopelvic disproportion, caesarean more convenient and no risk of unknown (would overall prefer vaginal birth after caesarean section, but patient worried re chance of emergency caesarean section)” (Doctor)

“Thirty six weeks pregnant – Discussed risks of needing emergency caesarean section, elective caesarean section booked” (Doctor)
The doctors’ record of their discussions with the consumers implies that Site B is oriented towards practicing a paternalistic or medical model of maternity care. For example:

Twenty weeks “Patient (26 year old, fourth caesarean section) requests tubes to be clipped or tied post operatively or at time of surgery” (Doctor)

Thirty six weeks “Patient requests tubal ligation, discussed with senior colleague, not happy to offer tubal ligation at time of caesarean section due to age, could discuss again in gynae outpatient department” (Doctor)

Another example:
“Patient requests Trial of Scar, explanation to patient of risks of ruptured uterus, patient agreed to have elective caesarean section” (Doctor)

This data is of particular significance because it is the aim of this study to identify the practice of consumer participation through examining the medical records’ content for examples of clinicians and consumers sharing the responsibility of decision making in clinical practice. However, the findings indicate that in Site B the medical clinicians are the primary decision makers, whilst the consumers may only contribute by requesting information or asking the doctors’ permission. Ultimately, decision making power lies in the hands of the doctor. From another view, it can be assumed that the consumers’ obvious passivity in regard to decision making is actually their interpretation of the level of involvement available to them.

Site B’s Consumer Participation Themes

As detailed in Site A’s audit data, conjecture is limited to the documentation that is present rather than absent in Site B’s record sample. Hence, this section focuses on exploring the content or themes that are present in the implied or overt documentation sequences. This approach allows a clearer insight into the aspects of care that tend to be approached in a participative manner or significant enough to be reported in the medical record. Using Site A’s theme categories as a guideline, the data from each record is further scrutinised, grouping consumers’ responses to direct questions from
clinicians, paraphrasing of requests or statements made by consumers or evidence of discussion between the consumer/clinician. From the 39 records audited, 84 sequences of documentation have been classified into ten themes (Table 4.36).
Table 4.36 Site B’s Consumer Participation Themes

<table>
<thead>
<tr>
<th>Overt/Implied Consumer participation indicator themes identified in medical record sample (n=39)</th>
<th>Number of medical records with indicator themes evident in contents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal request for caesarean section</td>
<td>33</td>
</tr>
<tr>
<td>VBAC discussed</td>
<td>7</td>
</tr>
<tr>
<td>Feeding preferences discussed</td>
<td>1</td>
</tr>
<tr>
<td>Breech options discussed</td>
<td>8</td>
</tr>
<tr>
<td>ECV attempted</td>
<td>0</td>
</tr>
<tr>
<td>Tubal ligation discussed</td>
<td>9</td>
</tr>
<tr>
<td>Discharge plan discussed</td>
<td>4</td>
</tr>
<tr>
<td>Antenatal screening discussed</td>
<td>4</td>
</tr>
<tr>
<td>Anaesthetic discussed</td>
<td>1</td>
</tr>
<tr>
<td>Specific consumer requests (as per Site A’s data)</td>
<td>17</td>
</tr>
</tbody>
</table>

Table 4.36 represents the frequency by which each record’s documentation is related to a particular consumer participation theme or issue. The table is supportive of Site B’s previous documentation examples, in that their reference to consumer involvement is limited to the pre-admission/operative episode of healthcare, where clinicians’ documentation concentrates on describing medical procedures and gaining consumer requests for surgical intervention. Apart from requesting a caesarean section, there is minimal reference to the consumer as an active participant or being considered a partner in the healthcare experience.

Furthermore, the pattern of absence has been reinforced in the audit. This includes the absence of participation indicators in the post-operative and discharge episodes, the absence of documentation other than the provision of medical information, and the absence of evidence of midwifery care or the midwives’ interaction with consumers in fulfilling their maternity care role. One interpretation of this finding is that the involvement of, or
communication with consumers in the design of healthcare is irrelevant; furthermore, the contribution to healthcare by clinicians who are not members of the medical discipline is also irrelevant and not found in the medical record.

**Summary of Site B’s Consumer Participation Indicators**

The audit of the medical record for consumer participation indicators demonstrates that indicators are most likely to be evident in Site B’s pre-admission/operative episodes of care. The presence of indicators tends not to be associated with the document format, but rather it is dependent on whether medical clinicians deem it relevant to record the consumer's contribution to the healthcare episode. There is no evidence of consumer participation post-operatively and just three consumers are identified in their record as being involved in their discharge care.

The data describes Site B as being supportive of the traditional medical healthcare model. The asymmetry alluded to in Site A, is also noticeable in Site B. The data suggests that Site B is doctor dominated and clinical care is designed to accommodate this dominance. The prevalence of participation indicators documented by doctors is interpreted as a covert fear of litigation, rather than an indicator of overt inclusion of the consumer in designing care.

The significant absence of participation indicators, and the absence of any documentation other than that of doctors in the medical records, means that the level of consumer participation evident in Site B is considered to be representative of passivity. These assertions, and the other findings highlighted in this section, are further explored in the data triangulation and discussed in Chapter Five.

**Site C’s Medical Record Audit Findings**

Site C’s initial sample of fifty medical records have also been put through the study’s rigorous sampling and exclusion processes prior to being included in the final sample of records. Eleven records have been excluded from the study, leaving thirty-nine records to be audited. Each of the thirty-nine
records has been through the same structured audits detailed in Site A and B’s findings and in Chapter Three. To minimise repetition, each method of data analysis will be introduced briefly and then expanded upon if the findings are unique to Site C.

Site C’s Medical Record Demographic Data

The consumers’ demographic data identified in Site C’s record sample have been collated and grouped into a range of variables. The demographic data is presented as modal frequency and percentage of modal frequency (Table 4.37). The sample size prevents detailed analysis of individual variables.

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Range of Variable</th>
<th>Modal Frequency</th>
<th>% Modal Frequency of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Age</td>
<td>20 – 38 yrs</td>
<td>25 – 34 yrs (28/39)</td>
<td>72%</td>
</tr>
<tr>
<td>Birth Experience</td>
<td>First – Third Birth</td>
<td>Second Birth (19/39)</td>
<td>49%</td>
</tr>
<tr>
<td>Financial Category</td>
<td>Public - Private</td>
<td>Public (39/39)</td>
<td>100%</td>
</tr>
<tr>
<td>Clinical Indicator</td>
<td>First Birth</td>
<td>Breech presentation (10/12)</td>
<td>83%</td>
</tr>
<tr>
<td></td>
<td>Subsequent Birth</td>
<td>Previous C/S (21/27)</td>
<td>78%</td>
</tr>
</tbody>
</table>

Table 4.37 shows that Site C’s sample has a maternal age range that spans eighteen years, with a predominant age grouping of 25 – 34 years. The birth experiences of the women in Site C ranges from their first to third birth. Twenty-seven (69%) women are multiparous, with twenty-one of the women experiencing their second birth. In summary, the record sample is exclusively from the public (non-chargeable) financial category, the maternal age reflects the childbearing population, and the women in the sample are more likely to have experienced childbirth before, which is likely to have been a caesarean section.

The demographic variables provide a broad background of the population for Site C’s record sample. These are useful in determining the representativeness of Site C’s consumer sample and for comparison with Sites’ A and B data in the triangulation chapter.

Site C’s Indicators of Consumer Participation
The record audit systematically tracks Site C’s thirty-nine consumers through their healthcare continuum, looking for evidence of consumer involvement in information sharing and decision making. The audit approach is progressive, following the consumer through pre-admission/operative, post-operative and discharge episodes, and classifying each episode into the dominant participation indicator category evident in each record. In other words, for each record, each episode of the continuum is allocated one indicator classification (Table 4.38). From the sample of thirty-nine records, one hundred and seventeen episodes of care have been audited.

Table 4.38 Medical Record Audit: Evidence of Consumer Participation Indicators in Site C

<table>
<thead>
<tr>
<th>Episode</th>
<th>Absent</th>
<th>Implied</th>
<th>Overt</th>
<th>Total Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Operative</td>
<td>0</td>
<td>1</td>
<td>38</td>
<td>39</td>
</tr>
<tr>
<td>Post-Operative</td>
<td>31</td>
<td>4</td>
<td>4</td>
<td>39</td>
</tr>
<tr>
<td>Discharge</td>
<td>33</td>
<td>3</td>
<td>3</td>
<td>39</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>64</td>
<td>8</td>
<td>45</td>
<td>39</td>
</tr>
</tbody>
</table>

Table 4.38 shows that out of the 117 opportunities to document consumer participation across the record sample, there is evidence documented in nearly half (53/117) of the episodes of care. This means that in the other half (64/117) of the care episodes, evidence of the documentation of participation indicators is absent.

When the records are separated into the care continuum, the pre-admission/operative episode of care is the most likely to include the presence of either overt or implied indicators, with 39/39 (100%) of the records indicating evidence of consumer participation. In comparison, the post-operative and discharge episodes are more notable for their lack of consumer participation indicators with only, 8/39 and 6/39 respectively, indicating any presence of consumer participation.

Interpretation of Consumer Participation Indicators

Out of 117 opportunities to communicate or suggest any form of consumer participation across the continuum of care, documented indicators are present...
in fifty-three episodes of care. In other words, in sixty-four (75%) of the 117 care episodes there is no indication of information sharing, or the consumer being included in healthcare decision making, either by marking or signing a box designed to guide clinicians’ practice. Examples of overt and implied participation indicators for Site C include:

**Overt Indicators**

‘Discussed antenatal screening, has PCA scan booked for next week, only wants amniocentesis if high risk based on NT scan. Understands that NT scan does not completely exclude trisomy risk’ (Pre-admission/operative)

‘Continue PCA today and oral medication as per patient request. Review in AM’ (Post-operative)

‘Planning discharge today, baby artificially feeding in SCN, has now decided to stay and see baby’s progress. Family aware’ (Discharge)

**Implied Indicators**

‘Plans BF [breastfeed]’ (Pre-admission/operative)

‘Decided to AF [artificially feed]’ (Post-operative)

‘Keen to go home’ (Discharge)

Table 4.38 shows consistency in the documenting of overt indicators of consumer participation (97%) in the pre-admission/operative documents. In contrast, overt indicators have been identified in the post-operative documents of four records and in the discharge documents of three records. This finding is similar to those in Site’s A and B, which suggests that there are components of the pre-admission/operative episode of care that motivate both the clinician and the consumer to participate in some degree of obvious collaboration. It is also notable that these same conditions are not prevalent in the post-operative and discharge healthcare episodes.

In further reviewing the record sample and the participation indicators, it is also apparent that Site C shares another trait with Site B; that being, each record’s contents are dominated by medical clinicians. However, in contrast to Site B’s data indicating a preference for the medical model of decision making,
Site C’s documentation indicates that a shared approach to decision making is likely. This is particularly prominent in the pre-admission/operative episode, which not only includes comprehensive descriptions of discussions, but also evidence of evaluative feedback and of consumers influencing the design of their healthcare experience. Examples include:

Thirty weeks pregnant - ‘34/40 breech – options discussed, including risks, patient will decide next visit’

Thirty-seven weeks pregnant - ‘37/40 still breech, discussed ways of turning the baby, patient unhappy with these, patient requests an elective caesarean section’

And

Thirty weeks pregnant - “Discussed trial of scar v’s elective repeat caesarean, patient keen for trial of scar, will discuss with partner.

Thirty five weeks pregnant – “Patient now interested in induction of labour at term – discussed policy of waiting till term + 7 days explained”.

Thirty eight weeks pregnant – “Patient has decided she wants elective caesarean – have explained risks – did not want to hear them again”

Site C’s data supports the view that this site’s medical practitioners are demonstrating sharing the responsibility. The records indicate that the consumer(s) and the clinician(s) contribute to information sharing and decision making. There is also evidence that information sharing takes place over consecutive visits prior to decisions being made and that the documentation implies that both the consumer and clinician are open to negotiating the design of healthcare. However, it must be noted that these findings are most likely to be evident in the pre-admission/operative episode and often relate to one specific aspect of healthcare that is, gaining consent for surgery. Once consent has been formalised, evidence of participation swiftly disappears.

Similar to Sites A and B, an absence of evidence of consumer participation is a recurrent finding. The absence is in relation to the documentation of indicators
in the post-operative and discharge episodes of care, in particular absence of evidence of midwifery/nursing care or their interactions with the consumer.

Site C’s Consumer Participation Themes

As detailed in Sites A and B audit findings, conjecture is limited to the documentation that is present rather than absent in Site C’s record sample. Hence, this section focuses on exploring the content or themes that are present in implied or overt sequences of documentation. Using Site A’s theme category as the guide, Site C’s record samples have been reviewed again. Consumers’ responses to direct questions from clinicians, the paraphrasing of requests or statements made by consumers and evidence of attending to discussion of topics have been classified into thematic groups. From the 39 records audited, 131 sequences of documentation have been classified into ten themes (Table 4.39).

Table 4.39 Site C’s Consumer Participation Themes

<table>
<thead>
<tr>
<th>Overt/Implied Consumer participation indicator themes identified in medical record sample (n=39)</th>
<th>Number of medical records with indicator themes evident in contents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal request for caesarean section</td>
<td>38</td>
</tr>
<tr>
<td>VBAC discussed</td>
<td>6</td>
</tr>
<tr>
<td>Feeding preferences discussed</td>
<td>31</td>
</tr>
<tr>
<td>Breech options discussed</td>
<td>13</td>
</tr>
<tr>
<td>ECV attempted</td>
<td>2</td>
</tr>
<tr>
<td>Tubal ligation discussed</td>
<td>3</td>
</tr>
<tr>
<td>Discharge plan discussed</td>
<td>6</td>
</tr>
<tr>
<td>Antenatal screening discussed</td>
<td>5</td>
</tr>
<tr>
<td>Anaesthetic discussed</td>
<td>5</td>
</tr>
<tr>
<td>Specific consumer requests (as per Site A’s data)</td>
<td>22</td>
</tr>
</tbody>
</table>
Table 4.39 shows how frequently the particular themes have been documented by clinicians. As the indicators are predominantly located in the pre-admission/operative episode of care, the participation themes are also central to this episode. The participation themes demonstrate a preference for requesting caesarean section and discussing feeding preferences. Similar to Site A’s data, these preferences are representative of safe aspects of care for consumer involvement. In the other words it is safe and socially acceptable to discuss infant feeding preferences, it is also safe to involve consumers, allowing them to request an elective surgical procedure.

The participation themes and the examples of participation indicators identified in Site C show that, apart from the pre-admission/operative episode of care, there is minimal inference that consumers or clinicians are interested in pursuing participation further into the healthcare continuum. The potential for consumer participation that has been projected in the pre-admission/operative episode is once again sobered with the familiar pattern of absence; with the post-operative and discharge episodes being predominantly ‘absent’ of evidence of participation indicators.

**Summary of Site C’s Consumer Participation Indicators**

Site C’s consumer participation indicator audit demonstrates that evidence of involvement in decision making and information sharing is likely to be recorded in the pre-admission/operative episode of care. It is also likely that doctors will record the evidence of consumer participation and that participation is likely to be linked to requesting elective surgery. By comparison midwives/nurses record infant feeding preferences, and little else. It is also unlikely that in the remaining episodes of care there will be any further evidence of participation documented in the medical record.

The data implies that Site C is aiming to adopt a shared responsibility approach in the documentation of decision making in the pre-admission/operative episodes; however, this approach is apparently not sustainable beyond this episode of care. The data describes Site C’s approach as reflective of Bastian’s
restricted scope level of participation activity, where the consumer takes on a predominantly subservient role.

The asymmetry of involvement alluded to in Sites A and B, is also covertly evident in this site’s data, with participation indicators tending to be associated with what could be classified as safe aspects of care. This association may account for the preponderance of participation indicators identified in the sample’s pre-operative documentation and also for the fact that the practice of consumer participation is unlikely to mean that the design of clinical care is individualised beyond usual practice.

Therefore, the absence of participation indicators in just over half the episodes of care, despite the presence of indicators in the pre-admission/operative episode of care, is supportive of the level of consumer participation experienced in Site C being described as predominantly passive. These findings are discussed further in the data triangulation chapter.

The Medical Record Completeness Audit

Essentially the medical record completeness audit is useful as it explores the validity and reliability issues relating to the participation indicator data in the medical record by examining the completeness (lack of deficiencies) of the record and compares this assessment with another researcher’s finding. With this approach, I am able to explore the inter-rater reliability of the record’s data, as well as gain a greater understanding of whether the absence of consumer participation indicators is specific to the non-practice of recording consumer participation or is linked to clinician’s attitude to documentation in general.

The data collection and treatment processes used in this section of Domain Four have been clearly detailed in Chapter Three (pp.164-7). In brief, the audit tool is described as a patient centred quality improvement program designed to flag quality and safety issues through a medical record review methodology (QaRNS Review Manual 2000). The audit tool has been adapted to focus on
collecting data that indicates presence of documents or complete records (i.e. no evidence of incomplete documents).

Prior to the audit, the complete record sample is reviewed to identify the principal systems of documenting care. Across the study sites, two documentation methods stand out; firstly, the clinical pathway, with provision for clinicians to acknowledge the completion of standardised defined care processes with a signature notation, and secondly, the unstructured handwriting of the progress notes.

The absence of a signature(s) on the pathway or to accompany assessment forms/notes/reports is defined as the incomplete documentation of care. Absent documentation is defined as; the absence of evidence of notation of a clinically significant event (e.g. consent) or the absence of notation within the time frames for clinicians, as determined by the QaRNS criteria number 20 and 21 (QaRNS Review Manual 2000). Documentation legibility, including clinicians’ signatures and designation, are also assessed. To demonstrate inter-rater reliability, a Queensland Health medical record coding consultant (employed by the Commonwealth project) examines the identical sample of medical records.

Summary of Medical Record Completeness Audit Findings across the Three Sites

An overview of the data collection, including documentation and coding for each site’s medical record sample is presented in Appendix F. Due to the audit tool being a generic tool and there being numerous similarities identified in the data, the presentation of significant findings have been summarised collectively.

The documentation deficiency audit demonstrates that the assessment of presence and completeness of the medical record documents that I have made for this study is consistent with the independent coders’ data. Examples of consistency include: uniformity in assessment of the absence of consent forms (Site A); incomplete clinical pathways (Sites A, B and C); and, inconsistent discharge planning documentation (Sites A, B and C). Other
common findings are the difficulties experienced by both auditors when identifying completion of midwifery/nursing care (Sites B and C), and navigating Site C’s haphazard filing system.

The high degree of consistency between each of the findings is considered indicative of inter-rater reliability for the data collected from each site’s record sample. Minor discrepancies within the audit tables can be accounted for by: the independent coder auditing records that have been excluded from this study (Site A); being unable to access sample records (Site B); both auditors being unable to locate the clinicians’ documentation; and, the duplication of the clinicians’ documentation on numerous forms (Site C).

The Commonwealth project’s documentation deficiency audit covers the healthcare continuum documents and describes the record samples as predominantly inconsistent in completion and of questionable quality. This description reflects my consumer participation indicator audit findings of a predominantly absence of evidence and of superficial quality.

An interpretation of the data is that the medical record is an incomplete source of the healthcare experience. However, taking into consideration that the medical record is recognised as the most complete source of events and persons that influence a consumer’s healthcare experience (Wolf 1985), the absence of events being recorded in the medical record can be justifiably argued as an absence of the event occurring during the consumer’s healthcare experience.

In summary, the data demonstrates that the consumer participation indicator audit tool is capable of representing the level of evidence that is available in the medical record. Additionally, this implies that the absence of evidence of participation indicators is not just a limitation of the data collection method, but representative of the level of consumer participation experienced.

**Summary of Domain Four – The Medical Record**
This chapter has presented the evidence gathered through an examination of each site's medical record sample in order to document indicators of consumer participation in the design and evaluation of their healthcare. Furthermore, demographic variables have also been collated and the completeness of the record sample audited.

The participation indicator audit indicates that from the 357 episodes of care across the three sites, consumer participation (implied or overt) is only evident in 150 of these episodes. This means that in nearly 60% of the healthcare episodes, there is no evidence or even suggestion that consumer participation takes place. Individually, Sites A and C have an absence of participation indicators in half of their record samples, whilst Site B has an absence of evidence of participation in two thirds of their episodes of care.

The findings demonstrate that the incidence of indicators of consumer participation is significantly more likely in the pre-admission/operative episode than in the post-operative and the discharge episodes of care. Further examination of the prevalence of participation indicators highlights that the presence of them does not mean that the site has adopted a consumer oriented approach to healthcare. Instead the presence of participation indicators is mainly associated with the site’s preformatted documents.

Examining the content of the participation indicators further, it is evident that they tend to be associated with components of care that are safe to involve consumers in; meaning that their inclusion would not disrupt clinical care or the clinicians’ own practices. Furthermore, the participation indicators are noted to be characterised by an asymmetry rather than partnership in decision making. For example: Site A’s audit identifies that clinicians are more likely to document consumer participation in breast feeding preferences, than in anaesthetic choices; Site B’s participation indicators are used to fulfil the doctors’ perceived medical litigation requirements and reflects the traditional medical model of decision making rather than a decision making partnership; and, Site C’s audit suggests that the shared responsibility approach to decision
making is being staged to represent consumer participation in designing their healthcare.

In summary, participation indicators have been dominated by doctors’ documentation, there is an absence of indicators that significantly influence the design of care (i.e. discharge planning) and it is unlikely that the level of participation offered in the pre-admission/operative episodes will reoccur throughout the remainder of the consumers’ healthcare trajectory. The absence of evidence of consumer participation indicated in nearly 60% of the consumers’ healthcare episodes accentuates the implications of this data and signifies the study’s consumer sample are passive participants in their healthcare experiences.

Comparison of the study’s findings has been completed using the Commonwealth project’s validated screening tool, as a way to demonstrate reliability of the study’s data. The documentation deficiency audit describes each site’s medical record sample as typically being incomplete and of a questionable quality. Documentation deficiencies tend to be associated with the clinical pathway and the document filing format. These deficiencies are evidenced by an absence of collaboration between disciplines and in the organisation of clinical care.

The independent assessment of the medical record samples indicates that it is not uncommon that clinical care is not completely documented in the medical record. This may be considered a limitation to this study; however, the medical record is acclaimed as the most reliable retrospective source of people and events that influence the consumer’s healthcare experience, and it has also been argued in the legal arena that an event or action did not happen if it is not recorded in the record (Jamieson 1999). The documentation deficiency audit gives support to the study’s indicator audit findings. In other words it is likely that the absence of evidence of consumer participation in the medical record is representative of the consumer’s healthcare experience.
Data Triangulation

As stated in the introductory chapter, this study aims to determine indicators of consumer participation in the planning and delivery of healthcare in the Australian context. The intention is to determine the practice of consumer participation, by exploring whether an individual's healthcare experience has re-oriented from the traditional asymmetrical patient/doctor relationship, to a joint responsibility or partnership approach between consumers, the multidisciplinary healthcare team and the healthcare service.

In comparison to previous research this study's multi-source approach is unique; with the literature strongly supporting a triangulated methodology. This chapter's data, which spans the three sites within the study and is defined within the study's four Domains (Environment; Clinician; Consumer; Medical Record), have been triangulated. The comprehensive triangulations of the study data is attached in Appendix G.

Triangulation of the data is central to realising this study's aim. It allows for the documented reality of consumer participation to be deconstructed and then reconstructed within the social reality that frames the healthcare experience. The triangulation brings to the forefront the inter-dependence of data that has been collected, examined and discussed within the independent Domains of the study. For example, Appendix G’s triangulated data highlights that the presence and distribution of consumer participation indicators in the Medical Record Domain is a reliable representation of the level of consumer participation activity determined via the Environmental, Clinician and Consumer Domains. The triangulated data also substantiates that the absence of evidence of consumer participation indicators in the medical record audit, is a true representation of the evidence of absence of a participative orientation towards the consumer’s healthcare experience. Significantly, the data triangulation does not substantiate that joint responsibility is associated with the planning and delivery of healthcare.
Discussion of the study’s key findings, informed by the triangulation of the four Domains of data and compared with the literature, follows in Chapter Five.
Chapter Five

DISCUSSION OF STUDY FINDINGS

Introduction

In this chapter, the discussion of the study’s findings will be informed by the triangulated data (Appendix G) and compared with the literature. The discussion of the findings has been formatted using the methodology’s four Domains (environment, clinician, consumer and the medical record). However, in contrast to the previous chapters, the key findings from each site have been combined and summarised into statements that best represent the aim of each Domain. In addition, significant findings unique to individual sites have also been included in the relevant Domain’s discussion.

The reason why the study’s key findings are discussed in this way is because of an unexpected outcome; that is the continuous repetition of, and obvious relationships between, the data collected from three independent clinical sites. In fact, the triangulated data analysis reveals that the unique geographical and organisational structure of each site has had minimal influence on the study’s findings when compared to the similarities in the views and beliefs of individuals, and the organisational orientation towards consumer participation.

Domain One – The Environment

This domain focuses on the participative environmental attributes of the three hospital sites, and what influence these features are likely to have on the inclusion of consumers in information sharing and decision making throughout their healthcare experience.

The key finding from the triangulation of the environmental data is that, despite identifying a range of participative intentions and features conducive to facilitating participation across the sites, there is a lack of infrastructure and commitment to support consumers actively participating in their healthcare experience.
Triangulation of the environmental data reveals significant sets of data. This data was invaluable in providing the context to the study. It introduces the hypocrisy or mixed messages that appear to be deeply embedded in all levels of healthcare. The environmental data is discussed under sub-headings:

- Participative Intentions
- Clinician Views on Decision Making Partnerships
- Absence of Commitment to Consumer Participation Reforms
- Domain 1 – The Environment Summary

The intention of this approach to discussing the data is to allow what appears to be insignificant or eclectic data to be meaningfully viewed as to its influence on the practice of consumer participation in healthcare.

**Participative intentions**

Superficial Intent

The environmental data shows that despite each site endorsing some form of consumer participation, the participative attributes of the environment could only be described as somewhat superficial. The data puts context to Bastian’s (1994) description of consumer participation as being *window dressing*. To me, this means that each site’s participative intentions are unlikely to be capable of influencing the practice of consumer participation in healthcare. As *window dressing*, the organisation’s philosophy, policy or clinical documents contribute to both distracting and attracting the consumer. The *window dressing* indicates to those looking in, such as government, state or community bodies that the healthcare service has reformed and will continue to support reform in the provision of their healthcare services, whilst to those looking out, its business as usual.

In essence, the data indicates that across the study sites, there has been a superficial intent to lead service delivery reform towards the consumer oriented model.

**Restricted Scope of Participation Activities**
Bastian's (1996) five levels of consumer participation activity are defined by a propensity for engaging consumers in partnership in service and clinical planning, plus a propensity for improving consumer health outcome measures. Restricted scope is the third or middle level of activity. This level of participation activity does not support partnership, but implies that experts, such as healthcare professionals, are likely to be of the opinion that their views are representative of the consumers’ views (e.g. Site A – pregnant nursing staff acting as consumer representative on planning committee). Restricted scope means that consumer participation is a more ‘tokenistic’ than sincere pursuit of partnership. For example, healthcare organisations might promote or engage the consumer in activities that symbolise consumer participation, such as consumer satisfaction surveys; however, the consumer feedback or suggestions are not actioned or disseminated within the clinical area (i.e. Site A, B & C). The environmental data gave many examples of consumer participation being restricted from influencing the organisation of clinical care or health outcome measures. At best, consumer involvement is passive, a source or recipient of information (Bastian 1996). Restricted scope has also been used by Johnson & Silburn (2000) to describe the level of participation they identified when completing a snapshot of Australian Health Services. Johnson & Silburn (2000) found minimal evidence to support the development of working partnerships or service commitment to developing consumer participation processes.

In summary, the environmental data indicates the level of consumer participation activity across the three sites is likely to be restrictive and have marginal effect on consumer health outcome measures. Referring to Bastian’s (1996) data, the consumer may experience open involvement (possibility of partnership and improved outcome measures) through to manipulation (characterised by paternalism and minimal influence on outcome measures) during their healthcare experience.

Absence of Reform beyond Rhetoric

A critical feature associated with successful social and political reform, such as the adoption of the consumer participation philosophy in healthcare, is that service administration policy extended beyond rhetoric to conceptualisation in the practice of frontline healthcare (Bastian 1996; Johnson and Silburn 2000; AHMAC 1996). In other words, in order to reorganise from the traditional paternalistic
medical model towards a participative consumer oriented healthcare system and attain the maximum effect of the consumer participation philosophy, the reform process had to extend beyond statements describing intentions of consumer participation to individual actions and behaviours displaying participation. Significantly, in this study, each independent data source demonstrates that this critical feature is missing. Moreover, at each site, there is an absence of evidence that these processes are being considered, let alone being a feature of clinical care delivery.

Mixed Messages

The environmental data indicates that there is a significant level of contradiction and variability between each organisation’s purported participative philosophy to healthcare, the settings management orientation, the structure of clinical work and the clinicians’ own views and behaviours. The implication of these mixed messages is that within their experience of healthcare, consumers are likely to experience inconsistent approaches to information sharing and involvement in decision making.

The absence of evidence of shared views by either clinicians or consumers about what can be considered a consumer orientated approach to healthcare creates an environment where, trust, knowing, and sharing are absent (Andrist 1997; Berglund 1998). Consequently, it is likely that clinicians or consumers experience frustration, and are then unable to identify a favourable participation outcome related to a specific healthcare episode. Thus, the environment stands out as a likely contributor to the inconsistent and superficial nature of the consumer participation indicators in the study’s medical record samples.

Risks of Sustaining Passive Participation Level

The study’s multi-method design has enabled me to make direct and indirect links between the potential for adverse health outcomes and the level of participation activity. Examples of such links include: the absence of evidence of any cross referencing of expected length of stay, across the care trajectory, represents an inappropriate service provision; the incomplete or absent risk management documents such as pre-operative checklist and surgical consent forms marginalise the safety and quality of healthcare; and consumer dissatisfaction with their
involvement in decision making is associated with unfavourable health outcome measures.

The environmental data demonstrates that the traditional healthcare environment and closed approaches place the consumer at risk of experiencing inadequate or inappropriate service provision (Cleary et al 1989), unsafe or poor technical quality of clinical care (Wilson et al 1996) and adverse physiological, behavioural or subjective health outcome measures (Kaplan et al 1989a).

Local and National Ambivalence

An absence of consistency in the evidence of consumer participation attributes found within and between each of the sites is comparable to the absence of consensus towards consumer participation that exists across the nation. The Australian Institute for Health and Welfare's (AIHW 2000) biennial report, states that a lack of consensus at a national level has foiled numerous attempts to determine standardised measures of consumer participation Australia-wide.

So, as the impediments to implementing, monitoring or benchmarking participative strategies by individual healthcare organisations continues to be debated nationally, individual healthcare organisation are the ones responsible for determining how they measured participation strategies, and reported their contribution to the quality and safety of healthcare. With the debate in progress, the lack of national consensus has emerged as a likely contributing factor to this study’s findings. For example, the environmental data demonstrated limited organisational capacity to reorientate or lead healthcare reform, let alone capture and report upon it. This inadequacy and lack of clear direction has been linked by Walsh (1999) to organisational ambivalence towards committing to consumer participation strategies beyond the agenda level. It presents an excuse for inaction, or perhaps exemplifies Bastian’s ‘window dressing’ approach, discussed earlier.

Absence of Commitment

Reinforcing the implications of an absence of consensus or leadership, the absence of commitment to reorientating the current model of healthcare towards the consumer oriented approach to healthcare, was a recurrent finding across the
study sites. The findings describe approaches to reorientation as being predominantly *ad hoc*, with limited resources and minimal consideration given to staff development or consumer training programs. This data mirrors the little or no commitment to the development of participation processes that Johnson and Silburn (2000) found in their snapshot of Australian Health Services.

This study's data triangulation is supportive of Johnson and Silburn's (2000) recommendations that it is *unlikely* that any commitment will be generated towards changing traditional, or existing clinical practices and views, without consideration of developing the infrastructure, allocating resources to stage the implementation, and consultation with key stakeholders (i.e. managers, clinicians and consumers).

**Clinic Views on the Decision Making Partnership**

In determining the participative environmental attributes of the three hospital sites, the clinicians’ intentions regarding the involvement of consumers in clinical care are clearly stated in their responses. Despite the diversity of views within each professional groupings, a trend emerged within and across groups, in that it was deemed appropriate to *consider* the needs of the individual consumer, rather than to *involve* them in healthcare related decisions. For example, within the study's clinician sample (n=102), 83% considered it appropriate that the clinician designs clinical care that is acceptable to the consumer, compared to 43% agreeing that the consumer should actually be involved in the design process. These findings reiterate that it is more likely that the consumer’s healthcare experience is directly influenced by the clinician’s perception of consumer needs, rather than the consumer being provided an opportunity to actively participate or *voice* individual needs.

**Preserving Paternalism**

Across the samples, the clinicians’ *preferred* approach to decision making is where the healthcare provider took principle responsibility for it. This preference demonstrates that paternalism remains a factor in contemporary healthcare decision making (Charles et al 1999). The findings also support Glare and Tobin’s (2002) recent report that healthcare providers remain motivated to preserve traditional decision making approaches, and that it is still considered a *fundamental*
right of the provider to choose which treatment options they offer to the consumer. Furthermore, the findings suggested that the link England and Evans (1992) made between the providers’ determination of a positive self-image, their job satisfaction and their perceived level of decision making power continued to be significant, at least for the sample of clinicians in this study.

The environmental data indicated an absence of evidence to support the view that the sites in this study placed any importance on assisting clinicians to explore the intrinsic or professional rewards related to practising consumer participation. The consistency in clinicians’ views against sharing responsibility in designing clinical care indicates that the healthcare workforce requires substantial incentive before they would consider waiving their autonomy and other such attributes perceived to be beneficial of their professional status (Woodward 1998). The irony is that in environments (i.e. Site A, B & C) riddled with inconsistencies, the paternalistic approach to healthcare decision making, is the only constant variable.

The clinicians in this study showed a preference for the paternalistic approach to decision making. The data does not claim to predict whether the healthcare workforce has the capacity to reorientate their clinical decision making practices to a more participative approach; however, the clinicians’ preferences do suggest a lack of preparedness to changing their behaviour. In fact, the views and behaviours reported by the clinicians correlated with what Bishop (1994) described as the mini drama of healthcare; where resistance to change is associated with the provider’s perception of being forced by the imposed policies of their powerful organisation and their managers, to regulate behaviours. The findings reiterate that it is unlikely that clinicians would commit to changing their traditional decision making practices and views, no matter how they felt about involving the consumer in their care.

Absence of Reason Increases Resistance, Decreases Effectiveness

In effect, the environmental domain shows that the clinician’s interest in engaging in participation activities was proportionate to their intrinsic motivation (meaning and values) and the level of environmental support for consumer participation. In other words, the resistance or ambivalence of individual clinicians’ to changing their decision making approach, was proportionate to the lack of regulation of
philosophy, infrastructure, or clear purpose to support the adoption of the participative approach to healthcare.

An example of where the adoption of a different approach within healthcare was marginalised by a lack of clear purpose or regulation is provided by Patterson and Sinclair’s 2003 study on the effects of a woman-held antenatal record on continuity of care in a rural Australian community. The intentions of the woman-held antenatal record were to facilitate involvement and continuity of maternity care in a setting where the continuity of carer was unlikely (Patterson & Sinclair 2003). The study’s evaluation on the use and effectiveness of the women-held record implied that the function of the record had not been clarified to the stakeholders (i.e. the service, caregivers or women). Consequently, the record was inconsistently completed and those clinicians who adopted the form modified its purpose to suit their practice. Additionally, instead of facilitating involvement in care planning, women reported receiving mixed messages from their caregiver(s), and did not perceive ownership or responsibility for their antenatal records contents. Instead, they perceived that the woman’s role was to simply carry the record for the benefit of their hospital/doctor. Consequently, 93% of the healthcare providers in Patterson and Sinclair’s (2003) study perceived that the woman-held antenatal record was useful and positively influenced the continuum of care, whereas only 36% of the women believed that holding their record had a positive influence on their pregnancy care. This left two thirds of the woman reporting that holding the record had ‘no effect’ on their pregnancy care.

In exploring the implementation of the women-held record, Patterson and Sinclair (2003) found an absence of evidence of debate or clarification of the purpose of the record with key stakeholders; this meant that its implementation was by policy makers and experts in isolation. As a result, the intended purpose of the women-held record was lost because of misinterpretations by stakeholders. An absence of debate about the relevance of the function (continuity of care and information sharing) when introducing the reform (woman-held antenatal record) means that the development of strategies that are supportive of the reform’s function are often neglected.
Johnson & Bament (2002) made a similar association in their exploration of consumer participation strategies in a Victorian healthcare setting. Their study identifies that an organisation's participation strategies or reform efforts, have had limited effect on clinician behaviours. Managers, clinicians and consumers are described as experiencing frustration and/or unrealistic expectations, which may be accounted for by a perceived deficit in capacity or skill, compounded by a lack of direction or purpose for adopting the participation strategies. The authors aptly describe this scenario as representative of the risks related to bypassing the form to follow function pathway (Johnson & Bament 2002).

The Form to Follow Function Pathway

Johnson & Bament’s (2002) form to follow function pathway has a number of implications for this study; therefore, it seems relevant to describe my interpretation of this pathway in the context of this study. Form may represent any reform intended to influence the practices, values and beliefs of a population. For example a form may be a document (clinical pathway); behaviour change (shared decision making); service delivery (multidisciplinary clinical team); or philosophy (consumer oriented model). Function is the purpose or reason for the form. Function is dependent on the facilities’ and stakeholder’s access and capacity to prepare, implement, and measure the form. Only after the infrastructure and consensus as to the function of the participation strategy has been confirmed, should the form be introduced. The form reflects the function, providing structure, guiding the implementation and evaluation of the strategy.

In the context of this study’s data triangulation, each sites’ intentions to progress towards the consumer oriented approach (form) has had minimal impact on either service delivery or clinicians’ views / behaviours (function), suggesting that the ‘form to follow function’ pathway has been bypassed. In relating both Johnson and Bament’s (2002) and Patterson and Sinclair’s (2003) findings to this study, a pre-requisite to embarking on the reorientation of service policy and delivery towards the consumer oriented approach would be to clearly state why the reorientation is necessary, making the benefits obvious. Collaboration and debate is required to give the function ownership within the organisation’s/workforce’s culture. It is important to note that when determining function, a workforce’s
capacity must be considered, and commitment secured to developing that capacity. This will provide the direction and infrastructure for development of forms, such as policies, procedures and documents, designed to modify workforce behaviours.

The study’s environmental data did not identify ownership, at any level, for ensuring the workforce had the capacity or motivation to reorientate their clinical practices towards increasing consumer participation in healthcare decision making. However, such a denial to address these prerequisites and the propensity for such a denial to result in undesirable outcomes is not unique to these healthcare organisations or this intervention. Production industries for example, have recently identified that the immediate benefits associated with taking shortcuts to improve productivity often result in regret and a poor quality product (Chatterjee et al 2002). I assert that by avoiding underlying issues, or failing to ascertain the capabilities of the industry to sustain interventions (such as adopting a consumer orientated approach to healthcare), means that benefits associated with the intervention are likely to be short lived and changes in practice or service delivery will not be sustainable.

In essence, the study’s triangulated data supports the argument that it is an unwarranted expectation that the clinicians embrace the behaviours, believes or values required to adopt a consumer oriented approach to healthcare into their clinical practice, in preference to their traditional practices. Additionally, in comparison to similar and different organisations’ approaches to introducing change, it is an unwarranted expectation that these organisations took the participatory pathway, such as defining the function of consumer participation in their service, prior to circulating the forms (guidelines and clinical pathways) intended to modify practice or service delivery. Therefore, with the benefit of this insight, the study’s incomplete documents and the absence of evidence of consumer participation should not be unexpected.

Absence of Commitment to Consumer Participation Reforms

The presence of a shared responsibility approach to decision making is a fundamental component of the consumer oriented healthcare model and this study’s findings indicate that the decision to facilitate consumer involvement in
planning of clinical care has not been a shared responsibility. Likewise, the absence of any commitment to consumer participation reforms has been demonstrated in the study by: inadequate access to leadership or resources (e.g. ineffective clinical pathways); any implementations being token gestures (e.g. discharge planning not linked to clinical care design); and the practice of avoiding complaints (e.g. feedback on housekeeping issues, rather than reviewing the quality or provision of healthcare as perceived by the consumer).

Furthermore, the findings demonstrate that even when consumers are provided with the opportunity to contribute to service and clinical practice design, the impact or visibility of this contribution is minimal. The environmental data highlights the absence of organisational infrastructure committed to guiding the collection, analysis and dissemination of consumer feedback. In addition, the data from the clinician and medical record audit indicates that consumer feedback is not fed back to clinicians or likely to impact on clinical care. In essence, the consumer is being used predominantly as an information supplier, and it is unlikely that consumer input is ever intended to be responded to, or used, to influence the organisation of clinical care.

An example of an adverse influence linked to token strategies can be found in Site A’s environmental data, where the organisation’s philosophy and policy documents indicate overt intentions (i.e. participative and collaborative strategies) to be in place. However, these intentions are overshadowed by an underlying traditional medical approach to the governance of clinical care. In this setting it is likely that consumers might perceive that they would be participating at an active level, but the environment could only offer isolated superficial or passive levels of participation in their healthcare experience. Of the three sites, Site A’s consumer sample was the least likely to be satisfied with their level of involvement in decision making, even though they are the most likely to report full involvement in them. In light of the triangulated data, this contradiction suggests that the consumer is dissatisfied with the mixed messages they receive as their involvement has no impact on their clinical care. Their dissatisfaction is an expression of their frustration of the façade of the environment’s participative intentions.
The relationship between consumer satisfaction with their level of involvement in decision making and the presence of a consistent and transparent approach to clinical decision making, is further supported by Site B’s consumer findings. In this site the organisation is upfront and consistent in stating the [restricted] level of participation that could be expected (e.g. ‘Obstetrician will discuss the options of antenatal care available to you.’). Significantly, Site B’s consumer sample is the least likely to report full involvement in decision making, yet the most likely to be satisfied with their involvement in them. This finding suggests that a favourable or satisfied interpretation by the consumer is linked to an environment where constant messages are transmitted and received throughout the health experience. Together, this data illustrates a major finding of this study; that is, any measure of consumer satisfaction must be associated with an insight into the expectations of that particular consumer.

Matching Expectation with Experience

The implication of matching consumer expectation of service delivery with the experience of the service delivered is seemingly obvious. However, I did not expect to find that consumers who report full involvement in clinical decisions (i.e. optimal environment) are not always satisfied with that involvement. Conversely, consumers who report less than full involvement (i.e. sub-optimal environment) are actually satisfied with that involvement. In reviewing the variable consumer ratings, it seems that the most influential attribute associated with their healthcare experience ratings, is not the level of involvement in decision making activities, but whether there is consistency in the consumer’s interactions with the healthcare environment and workforce. This is an important consideration when attempting to define attributes that are likely to contribute to a positive consumer outcome measure, or a consumer oriented approach to healthcare.

The findings imply that it is an unwarranted expectation that consumers will be satisfied with being fully involved in healthcare decision making. This data raises the question as to whether consumers have been consulted about the attributes that positively influence their healthcare experience, or whether the impetus for facilitating greater involvement in healthcare decision making is a consumer driven initiative. Alternatively, it may be the experts’ interpretation of what they
consider reflects consumer needs, which is representative of Bastian’s (1996) restricted scope.

An alternative view on the triangulated data and the predominantly passive level of participation that is evident across the study sites may be that the consumer is not committed to sharing the responsibility of healthcare, or perhaps that consumers do not have the opportunity to share how they feel about, or if they value, being involved in decision making activities. This may explain the environmental data’s passive level of consumer involvement as being representative of the consumer’s preference. It may also account for the clinicians’ ambivalence in involving consumers in designing their clinical care. Exploration of these issues is beyond the scope of this study; however, they remain significant issues to be considered in the recommendations for further research.

Traditional Roles Reside

The findings suggest that the contemporary ideas about consumers taking an active role in their healthcare experience, rather than the traditional sick or patient roles are not evident. In practice, the idea of taking joint responsibility in healthcare is not a priority of the healthcare professional and may not be a priority of the healthcare consumer either.

The ACSQHC (2000) presented a global vision, prioritising the need to renegotiate traditional healthcare roles so that they reflect a shared responsibility structure, thus improving the safety and quality of healthcare. This study’s findings indicate that the traditional patient roles have not yet been replaced with attributes that reflect an active level of participation, such as joint problem solving, joint decision making, and joint responsibility (Consumers’ Health Forum of Australia 1990; cited in Bastian 1994). The findings indicate that consumer satisfaction measures are not necessarily representative of the participative attributes of the healthcare relationship, or in fact of healthcare quality. Finally, the data from this study questions whether shared responsibility in healthcare decision making is a priority for the healthcare consumer at all, or if it is an unwarranted expectation.
Summary of Domain One Discussion

The environmental data’s key finding is that despite describing a range of participative intentions, each site is limited in its capacity to commit, or to consistently support, either consumers actively participating in their healthcare experience or strategies likely to improve consumer health outcome measures.

The evidence of participative attributes has been described as *window dressing* which distracts the consumer and *others* from the actuality of the environment. This is a reality which predominantly reflects the *restricted scope* level of participation, which features involvement in decision making based on the medical *expert* model.

Environmental features that restrict each site’s *participative* intentions include: a service design that directs consumers to engage in traditional *patient* role decision making; clinical documents that encourage a paternalistic medical model of decision making; and a lack of leadership, purpose or measures likely to induce accountability to explore or engage in partnerships with either other disciplines or healthcare consumers. In relating these restrictions to Johnson and Bament’s (2002) *form to follow function* pathway, the environmental attributes and the behaviours of the clinicians and consumers should not be surprising.

An unexpected finding from this domain is that the site that demonstrated the *least* participative environment has been awarded the *highest* level of satisfaction with involvement in decision making by their consumers. This finding suggests that a priority for the consumer is the provision of a consistent and transparent approach to clinical care; thus, the minimal evidence of participatory or feedback strategies, and the organisational intention of *educating* or *using* the consumer as a passive information source are apparently irrelevant in the consumers’ *satisfaction* rating. This finding highlights that a positive consumer outcome measure [satisfaction] is associated with the *matching* of the consumer’s expectations and experiences. Shared responsibility, or active inclusion in decision making, does *not* appear to hold the equivalent *value* to that of consistency and transparency in clinical care for the healthcare consumer.
In relation to this study, the findings suggest that a one-dimensional approach to interpreting consumer satisfaction ratings is *not* appropriate for determining the level of involvement in decision making. The question as to whether the shared responsibility approach to healthcare is a priority of the consumer, or representative of the *restricted scope* of consumer participation (i.e. where the experts prioritise the consumers’ needs), is beyond the scope of this study. However, this quandary will influence my recommendations for further research.
Domain Two – The Clinician

This domain seeks to determine if the views and behaviours of the clinicians in the study are supportive of the consumer oriented philosophy, and what influence these behaviours have on the inclusion of consumers as partners in their healthcare experience.

Participative Behaviours

The triangulated data from this Domain highlights that this sample of clinicians report their clinical practice (both views and behaviours) to be representative of traditional self governing healthcare practitioners who tend to be inattentive to the quality, legal or collaborative aspects of their practice. The data indicates that the clinicians tend not to commit to: providing the standardised trajectory of healthcare proposed by organisational documents; communicating both clinical and consumer initiated variations in care; or, coordinating healthcare through the sharing of standardised information with consumers and their colleagues. This is despite the demographic data of the sample (n=102) which states that as a professional workforce they are typically tertiary educated (75%) and permanent employees (89%). These attributes are commonly considered precursors of a contemporary workforce that has a standardised awareness of the sites’ organisational, clinical and communication pathways (and perhaps even their views and behaviours may tend to be standardised). In other words, the data contradicts itself; rather than enabling a contemporary environment where consumers are actively participating in information sharing and decision making activities, as suggested by the demographics, the clinicians’ traditional and fragmented views and behaviours presents a chaotic environment, uninviting to the consumer.

Awareness of Documents is a Poor Predictor of Compliance or Completion of Documents

The triangulated data demonstrates that claiming awareness of hospital policy or clinical documents, does not necessarily translate into views that reflect those policies or behaviours that ensure completion of those documents. For example, 72% of the clinicians state they are aware of a standardised document that organises clinical care in their clinical setting however, when exploring the behaviours of the
aware clinicians, 40% of them do not regularly use it, and 47% do not record clinical practice variations in it. Significantly, the clinicians’ know that they do not routinely complete documents designed to organise clinical care. The significance of this finding is magnified by the clinicians’ awareness and use of information sheets replicating their previous responses across the sites. These findings suggest that the sites are likely to feature incomplete clinical documents, inconsistent sharing of information and an environment that is not only fragmented but is likely to be of questionable quality and safety.

With the benefit of a multi-method approach, the data indicates that the inconsistent documentation of clinical care is supported by the medical records’ poor standard of documentation. Furthermore, the inconsistent documentation is intentional, because the clinicians are aware that they neglect to record or communicate patient care. The absence of evidence of accountability to document variances in clinical care, or to supply standardised information to consumers or colleagues, indicates a disregard for clinical protocols and for meeting legal documentation obligations. The clinicians’ ambivalence and absence of accountability has both professional, employment and legal implications. In exploring the findings, I could not unequivocally state the clinicians’ responses to be either a conscious avoidance of accountability or ignorance of the legal ramifications of such (in)actions; however, this remains a significant finding of the study.

The clinicians’ views and behaviours can also be linked with the form to follow function pathway discussed in the previous domain’s data in that the form (e.g. clinical pathway) may not be used because the individuals (e.g. healthcare providers) do not relate to its function. This implies that the clinician may not have been consulted, engaged in designing or perceive they have the capacity to implement the function hence the form is avoided.

Compartments of Care

Triangulating the findings also identifies that the practices reported by the clinicians are an indicator of the Environment Domain’s restricted scope. The organisational walk-through data demonstrates that apart from the pre-admission period, each site’s organisation of care and clinical documents tend to
compartmentalise care into discipline specific sequences (or even ignore the contribution of specific disciplines). This means that rather than the consumer experiencing a seamless progression through the healthcare trajectory, attended to by a collaborative multidisciplinary healthcare team, the consumer is likely to be confronted with a disjointed matrix. The data demonstrates that any collaborative or participative behaviour that are reported is likely to be confined to the organisation of clinical care in the pre-admission period. This suggests that, even in a small way, the function of a participative environment has been accepted and adopted in the clinicians’ pre-admission behaviours (i.e. taken form). The triangulated findings also suggest that clinicians have developed a method of framing participation in the pre-admission documents; consequently, in contrast to the absence of evidence in the post-operative/discharge documents, consumer participation indicators are evident in the pre-admission documents. Because participation implies a two-way process, the data implies that consumers are more likely to be socialised in relation to being asked to participate or willing to participate in the pre-admission episode of care rather than the post-operative/discharge episodes. The concept of restricted behaviours will now be explored in more detail.

**Restrictive Behaviours**

The findings indicate that the restricted participative intentions identified in the Environmental Domain, are evident in the clinicians’ views and behaviours. Obvious similarities include:

- profession based structure of clinical work
- medically focused clinical management
- minimal accountability for reviewing the quality of one’s own practice at the clinical unit level

A key finding from the data is that the evidence of absence of indicators of information sharing or involvement in decision making in the medical record findings is unlikely to be simply indicative of poor documenting behaviours by clinicians. Rather, the findings are representative of an absence of evidence of a standardised approach or sharing the responsibility of healthcare within the views and behaviours of the clinician sample. Unfortunately, due to the range of
clinician responses across the healthcare continuum, I cannot unequivocally confirm or deny the participative nature of individual clinician’s approaches to decision making from this study. Significantly however, the data triangulation does indicate that the generic inconsistency in clinicians’ views and behaviours is not only likely to restrict the level of participation activity experienced by the consumer, but that they are contributing factors to the questionable quality and safety of healthcare documented in the medical records.

Self- Governance of Clinical Practice

The triangulated data identifies a link between clinicians having access to a restricted range of standardised multidisciplinary documents and the likelihood that clinicians are aware of organisational policy and/or documents. However, this awareness does not necessarily translate into coordinated or participative clinical practice. In fact the findings suggest that clinicians’ views and behaviours are independent of organisational documents, employment status, and level of education or legal accountability. Thus, the variable survey responses within disciplines, and across sites, indicates that clinicians tend to self-govern their clinical practice. This suggests that clinicians’ views and behaviours reflect their own interpretation or motivation to be accountable to their legal documenting obligations or to practice within a collaborative or participative healthcare model.

The interpretation of these findings contradicts the literature, which generically states that clinicians practicing within the maternity care setting are willing to practise within a collaborative framework (NHMRC 1996), and are committed to developing a mutual participation approach to clinical decision making in comparison to other speciality areas (Mead & Bower 2000). Furthermore, the findings also challenge the concept that ECS is representative of a predictive consumer centred environment that is likely to demonstrate characteristics that will facilitate the essentially young, healthy consumers’ inclusion in decision making and information sharing activities (Roach et al 1998; de Costa 1999). Similar to the literature that questions how collaborative the ECS environment is, the triangulated data describes clinicians’ approaches to clinical care as fragmented, with clinicians tending to favour self governance. These approaches are described in the literature as being predictive of a highly interruptive environment that reduces the effectiveness of clinical communication, increases the incidence
of clinical error, adversely influences healthcare quality and places each clinician at risk of facing medical negligence claims (Robinson & Compton 1997; Jamieson 1999; Parker & Coiera 2000; Degeling et al 2000).

There is also an absence of evidence in the findings to support Turnbull et al’s (1999a) generalisation that maternity care clinicians possess a generic knowledge and belief about engaging consumers in participation strategies. Rather, the findings support McMillan’s (2001) scepticism of the taken for granted attitude by those leading consumerism in healthcare reform, that it is a given that clinicians are willing, or capable, of collaborating or reconceptualising their professional roles into a multidisciplinary consumer orientated approach to healthcare.

Strategies for Clinician Behaviour Change

Beyond raising awareness of already implemented forms, there is an obvious absence in the sites of any regulation or leadership to assist clinicians to interpret, and guide the integration of participation strategies, into clinicians’ practices. This is an often quoted stumbling block when attempting to change clinicians’ behaviours towards adopting more participative approaches in healthcare decision making (McMillan 2001). Johnson and Silburn suggest that to support behaviour change in clinicians, organisations need to provide clinicians with a purpose (function) for change (2000). A recommendation is to develop an infrastructure that provides both purpose and acknowledgment of the knowledge and skills required for the clinicians to practice collaboratively (with each other and with consumers), whilst also facilitate the association of values and rewards that pre-empt behaviour change in clinicians (Bastian 2000). Likewise, Walsh (1999) suggests developing links between consumer participation strategies, clinicians’ contribution to the consumers’ experience and health outcome trends as a means to break through and activate change in clinicians’ behaviours.

In summary, the triangulated data demonstrates that clinicians believe that their professional and legal accountability to communicating clinical decision making with either colleagues or consumers is self-governed (independent interpretation and regulation of responsibility). The absence of evidence of individual clinicians demonstrating, either a collaborative or standardised approach to healthcare, is a
reliable representation of the restricted scope level of consumer participation identified in the environmental domain.

**Discipline Specific Communication Preferences**

The data highlights that participative attributes of individuals within the clinician sample varies considerably. However, the emergence of response patterns is significant, with the data demonstrating trends within discipline groupings. The clinician data, when examined in discipline groupings, identified preferences for using traditional opportunistic methods to communicate progress in, or completion of, clinical care. The data did not support preferences for systematised communication methods (e.g. multidisciplinary meetings) or integrated standardised documents (e.g. clinical pathways); preferences that are associated with effective communication behaviours in contemporary healthcare.

Significantly, the data is not able to identify a method of communication that incorporates each of the discipline groupings’ communication preference. The data did however, demonstrate that a discipline specific communication ethos exists. The absence of shared preferences or methods of communication between disciplines suggests that efforts to evaluate healthcare communication would be a complex feat. The data from this study demonstrates that doctors prefer verbal or discipline specific ward rounds to communicate clinical care, and if this is the only way clinical care is to be communicated, then other disciplines, consumers and researchers are likely to experience difficulties planning or evaluating healthcare.

The evidence of a discipline specific communication ethos is also evident in the clinical specialities within discipline groupings. For example, within the grouping of nurse the preferred method of communicating and organising clinical by the theatre nurses’ is, knowing the individual doctor’s preferences or referencing clinical protocols/guidelines; whereas midwives prefer to utilise the range of methods, although the clinical pathway is the favoured method. Similar to the doctors’ communication behaviours, these findings indicate that attempts to evaluate the continuum of clinical care will be obstructed by these communication methods, i.e. an audit of the clinical pathway document would not be representative of the clinicians or clinical practice experienced in that healthcare
episode. This is because only midwives claim to routinely use the pathway document to communicate or organise clinical care.

Communication Boundaries

In exploring the data, I am unable to determine whether the discipline specific communication ethos was a symptom, or a cause. In other words, do the clinicians possess ineffective communication behaviours or are the behaviours a product of the traditional medical model of healthcare? The traditional model is often characterised by each clinical discipline demonstrating distinctive traits that support their profession's interests, priorities and perspectives (Page 1999); thereby, fragmenting the disciplines into sub-cultures (McKenna 1995; Degeling et al 1998). Nevertheless, the absence of evidence of a preference for similar communication methods suggests that it is likely that consumers experience duplication, omissions or variations in approaches to clinical care because each discipline interprets, prioritises and communicates clinical care based on the interests of their professional grouping, irrespective of the needs of the consumer.

The data suggests that clinicians’ behaviours contribute and sustain communication boundaries, which subsequently contribute to fragmenting both clinical practice and the consumer’s healthcare experience. This means that in contrast to a continuum of healthcare, that assumes open communication and collaboration between providers, this study exemplifies a discipline specific communication ethos that compartmentalises healthcare. In addition, the consumers’ rating of poor coordination at the boundaries of clinical care, when communication is required between discipline groups or services, indicates that the ineffective communication between clinical disciplines is so obvious that it is observable to the consumer.

These findings question whether, in their pursuit for consumer centred healthcare, Australian healthcare facilities are progressing towards a multidisciplinary approach to the structure and provision of clinical care (Berglund 1998, ACSQHC 2000) or if the traditional power and social hierarchy of the profession-centred models of healthcare are under threat (Mead & Bower 2000). The findings from the Clinician Domain demonstrates an evidence of absence of
these features and demonstrates an absence of evidence of any capacity to facilitate shared responsibility towards the provision of consumer centred healthcare.

**The Medical Record’s Role**

The study’s triangulated data has not isolated a preferred method of communication in common between the clinical discipline groupings, which complicates any plan of auditing healthcare communication or care planning. However, an aggregation of the individual clinician response ratings identify that the medical record is the most favoured method across the sites. From the ninety individual clinicians who responded, seventy always or frequently access the medical record when organising clinical care. Divided into clinical disciplines, 95% of midwives, 69% of doctors and 65% of theatre nurses claim to always or frequently access the medical record.

**An Appropriate Source, Albeit an Incomplete Source**

Two significant issues have been raised from examining clinicians’ communication preferences in the context of the study’s triangulated data. Initially, I was puzzled by the data, because individual clinicians’ state that the medical record is the most appropriate source of clinical information, yet they report poor documenting behaviours, a tendency to communicate clinical care opportunistically and fail to document variations in care. However, in the context of the triangulated data, the clinicians’ preference for the medical record began to make sense, given the findings of discipline specific documents, ineffective communication pathways and individualistic approaches to clinical care identified within and across the study sites.

This paradox is similar to Patterson and Sinclair’s (2003) findings where healthcare providers (general practitioners and midwives) claim the usefulness of a document (antenatal record) as the prime source for clinical decision making (maternal/fetal history), whilst also reporting behaviours and views that suggest the document is useless (the antenatal record was stated to be incomplete, difficult to decipher and the information present unlikely to compliment clinical practice). The authors argued that the providers’ perception of the antenatal record’s usefulness (98%), is because of the absence of any other methods to facilitate
cross discipline or consumer information sharing; thus, ‘the information, though poor in quality, is better than nothing’ (Patterson & Sinclair 2003)

Incomplete Record is a Complete Source of Consumer’s Healthcare Experience

The study’s multi-method data collection has been a recurrent significant feature in each of the issues raised and discussed in the Clinician Domain. Without this data, any absence of documentation in the medical record might have been generalised as poor documenting practices by clinicians and regarded as a limitation of the study.

The triangulated data confirms that the contents of the medical record not poor quality and incomplete. The findings also demonstrate that this is a reflection of the poor quality of healthcare that the consumer is likely to experience, at least in terms of consumer participation. Therefore, I assert that the absence of evidence in the medical record of participation indicators is likely to be a reflection of the evidence of absence of participative attributes within clinicians’ views and behaviours, and environmental orientation.
Reliability of a Multi-Method Approach to Record Audit

I consider that if this study had taken the traditional one-dimensional approach to analysing the medical record's content, the reliability of the data would have been in doubt. Generally, the outcome of one-dimensional audits of healthcare records is that the clinical documents are criticised for being consistently inadequately completed (Roach et al 1998 & Cowan 2000), or illegible (Draper et al 1986; Elbourne et al 1987; Cabral 1997). Furthermore, the incidence of an adverse event in the medical record is associated with errors of omission related to clinical decision making in 52% of cases (Wilson et al 1995). The implication of such findings is that the medical record audit is considered an unreliable data source (Adeyi and Morrow 1997 & Cowan 2000), and the recommendations for further studies focus on improving clinicians’ documentation compliance (Wilson et al 1995 & Roach et al 1998). In other words, if I had taken a one-dimensional approach to the record audit (neglecting to take into consideration the views or behaviours of those that documented events and the environmental context in which the document was completed), my findings and recommendations would reflect the rhetoric of the literature reviewed.

With the advantage of this study’s multi-method approach, instead of unreliable (one-dimensional audit findings) assumptions, I am able to construct a matrix that considers the absence, presence and construct of clinical documentation. In providing depth to the analysis of the data, exploring the data from an environmental, professional and consumers’ perspective, brings the focus of the study back to its original aim – identifying indicators of partnership and shared decision making in the healthcare environment.

Summary of Domain Two Discussion

In summary, the triangulated clinician data demonstrates that the communication and information sharing behaviours of the clinicians in this study are not representative of contemporary professional behaviours. On the contrary, behaviours of the clinicians generate doubt about their ability or willingness to share the responsibility of healthcare with the consumer.

This study demonstrates that the implementation of standardised documents and raising the clinicians’ awareness of these documents is unlikely to change their
behaviours or views in regard to using the documents in their daily practice. The clinicians' views and behaviours demonstrate a preference for paternalistic, self-governing behaviours, with minimal accountability to communicate with professional colleagues or consumers alike, as well as an unfavourable view of consumers actively contributing to clinical care decisions. The multi-source data analysis shows a preference for the discipline specific medical model of healthcare and demonstrates that any inconsistency in the medical record documentation or absence of inclusion in decision making is likely to be related to conscious omissions.

The clinicians' approach to clinical care has been described as compartmentalised, with definite boundaries. This approach is reflected in both the document format and the organisation of clinical care. It has been identified that it is only in the pre-admission episode that these boundaries merge. It is suspected that this merger exists because the clinicians acknowledge the function of participation in their professional practice and that all parties consider the consumer's participation in this episode is socially acceptable. However, there is no evidence in the following episodes of care that the function of collaboration or participation is being explored at any level.

The multi-method approach taken in this study leads me to conclude that the poor quality of the clinical documents, in terms of recording consumer involvement, is a reflection of reality; that is, clinicians report that they don’t involve the consumer and so the poor documentation reflects this poor practice. In a sense then, the accuracy of the data is supported, irrespective of whether such practice is considered poor quality of care.

Finally, the triangulated clinician data demonstrates a correlation between the absence of evidence of participative attributes in the behaviours and views of clinicians and the evidence of absence that the clinicians facilitate an active level of consumer participation in their clinical practice. The findings conclude that a reliable representation of clinicians' participative attributes, across the study sites, would be an absence of evidence of consumer participation indicators in the medical record.
Domain Three – The Consumer

The Environment and Clinician Domains illustrate that attempts to facilitate an environment or collect feedback relating to the level of consumer participation activity or the consumers’ healthcare experience, is likely to be unregulated and approached in an ad hoc manner. The reticence towards sharing the responsibility of healthcare with the consumer, challenges the suggestion that clinicians are supportive of the consumer oriented healthcare model across the study’s sites. This domain, explores the views of consumers who lived the healthcare experience; that is how they interpret participative behaviours of clinicians who cared for them and how they view their level of involvement in the decision making.

Consumer Capacity

This Domain’s data demonstrates the consumers’ capability to contribute constructive and relevant feedback in regard to their healthcare experience. Furthermore, consumers’ satisfaction with involvement in decision making is shown to be independent of their perception of being a partner in their experience, but is a multifaceted concept, influenced by an environment that is transparent and consistent.

The data also demonstrates the benefits of listening to consumers. The consumers in this study have demonstrated a capacity to:

- distinguish between the behaviours of different clinical disciplines
- express a view of clinicians’ behaviours based on their expectations of the discipline
- interpret the coordination of care between clinical disciplines
- provide an outcome measure that reflects the anticipated level of involvement in decision making

In essence the data triangulation asserts that it is the healthcare organisation, not the consumer, which lacks the ability to critically appraise health service delivery. The consumer just needs the opportunity to be asked and listened to.

Consumer Reflections
Cross-tabulation of the consumer survey’s (n=56) demographic data with the medical record data demonstrates that the consumers that consented and participated in this study are representative of the study’s population in general. This means that despite the difficulties I experienced in accessing the consumer sample, the sample is not just representative of a single demographic variable (e.g. primiparous or 35-44 years). However, due to the small number of responses, the consumer response frequencies can not be examined for specific demographic patterns or trends.

Aggregated Clinician Participative Behaviour Ratings

The consumer survey provides 224 opportunities, across the three sites, for consumers to share their views on the behaviours of the clinicians who contributed to their healthcare experience. Not surprisingly, the aggregated inclusive behaviour ratings indicate that either consumers experience inconsistent clinician behaviours (this is supported by the Clinician Domain data) and/or that each consumer has her own expectations of clinician behaviours. Either way, finding out more about the consumer’s experience from the consumer’s perception is a valuable exercise.

Overall, given that consumers have been provided with a five-point scale (excellent, good, just acceptable, poor and don’t know) for rating doctor’s and nurse’s/midwife’s behaviours, consumers tend to rate clinicians’ participative behaviours as good. The literature predicts that consumers are likely to make allowances when rating clinicians’ behaviours (Degeling et al 2000) and sacrifice quality in response to the perceived difficult conditions clinicians must work under (Wilson et al 1996). For these reasons, in this study, only an excellent behaviour rating is considered indicative of consumers experiencing optimal participative behaviours of clinicians.

The data highlights an obvious trend across the sites, in that the consumers (n=112) are more likely to consider information sharing with clinicians as optimal (46%), in comparison to how they view clinicians sharing decision making (31%). Likewise, consumers are more likely to give poor or sub-optimal ratings to clinicians’ shared decision making (21%) than to information sharing behaviours (17%).
The consumers’ experience is also vulnerable to the data contradictions (mixed messages) that have been a feature of this study’s data analysis. An example of mixed messages is the clinicians’ viewing consumer involvement in decision making as inappropriate, yet claiming that they base clinical care on what is appropriate for the consumer. As highlighted in the Environment and Clinician Domain data, the consumers’ views support Bastian’s (1996) restricted scope level of participation activity.

Rating of Discipline Specific Participative Behaviours

When asked to consider single discipline behaviours, consumers rate those of the doctors consistently less participative than those of nurses/midwives. Examining consumers’ responses to single discipline questions (n=56), shows that the doctors’ inclusion of the consumer in decision making is rated the least participative behaviour (28% optimal), followed by the doctors’ information sharing (46% optimal) behaviours. This finding supports the Clinician Domain’s conclusion that each discipline has distinct behaviours and that a discipline specific ethos exists. Therefore, I assert that to progress towards the consumer oriented collaborative approach to healthcare; measures are required to examine and address single discipline behaviour deficits as identified by the consumer. This approach is likely to be more effective than the multidiscipline reorientation strategies, designed by experts, that have obviously had limited influence on the traditional medical approach to healthcare.

Rating of Coordination of Care

Overall, the coordination of care between doctors and nurses/midwives has been rated the least participative by consumers (25% optimal). The consumers’ view that clinicians communicate ineffectively with each other, is supported by the clinicians’ own description of their communication behaviours. The clinicians’ data indicates that it is unlikely that consumers would witness the various disciplines communicating at the boundaries of care due to their separate preferences for particular communication methods, and predicts that clinical care experienced by the consumer will be interruptive rather than coordinated. The consumers’ data demonstrates that those who witness clinicians’ communicating at the boundaries, do not hesitate to rate it as sub-optimal.
Triangulation of the consumers’ data with the findings from the Environmental and Clinician Domains, reinforces that their hesitation to rate clinicians’ participative behaviours as optimal is representative of: ineffective clinical communication pathways; clinicians’ preference for self governance; and, a restricted scope for consumer involvement in healthcare. In other words the triangulated data reliably represents the consumer’s healthcare experience.

Information Shared, Yet Not the Decision

The data shows that although the consumers are inconsistent in rating clinician’s information sharing behaviours as participative, the consumers tend to view sharing of information as a more positive experience than clinician’s involvement of them in decision making. In comparison to the difference between the consumers’ ratings for information and decision sharing behaviours, there is an absence of evidence of this disparity in the contents of the medical records. This inconsistency between the consumers’ views and the events in the medical record supports the multi-method approach of this study. However, this method also poses numerous view-points as to why there is a difference in the data. For example, the clinicians may be unaware that their behaviours or the practice environment is not inviting of consumer involvement in decision making and are therefore unaware that the level of involvement by the consumer would be anything but passive. The clinician would then record involvement in decision making as a participative event in the medical record. Based on the data, I cannot unequivocally support this interpretation; however, the consumers insight into clinicians’ behaviours, is supported by Appleton et al’s (2000) findings that health professionals prefer sharing information to sharing decision making.

Appleton’s (2000) Australian multi-centre case review of clinician/consumer decision making relationships, explores women’s (with previous uterine scar) decisions between either elective caesarean section, or attempted vaginal birth. Not dissimilar to the present study, Appleton’s (2000) medical record data identifies information sharing as an obvious attribute of clinician/consumer preadmission relationships, and that women are often credited with making autonomous decisions and requesting surgery. Significantly, in reviewing clinicians’ actual preferences or motivation for women to choose one particular option, Appleton reports that the outcome of a woman’s decision making
processes is likely to mirror her clinician’s preference for a particular intervention (2000). This implies that the woman’s preferred option (choice) correlates with her clinician’s preferred intervention, which questions the autonomous nature of the decision. This level of investigation is not included in the present study; however, the triangulated data does not contradict that decision sharing is an area that deserves further study.

Interpreting the Consumers’ Experience

In relation to facilitating healthcare partnerships, the triangulated data supports Elwyn’s (1999) claim that the clinical environments are capable of supporting information sharing; however, it is not obvious from the data whether the critical attributes of open debate (de Costa 2001) or negotiation (Fitzgerald & Phillipov 2000) are fostered in the study’s sites. Comparing the consumer’s views with the medical record audit provides context to the consumer ratings and assists me in determining whether the medical record is representative of the consumer’s reflections. For example, clinicians’ documentation of consumer request is only evident in the pre-admission period and associated with doctors recording the justification for a surgical intervention. Not surprisingly, when a consumer reflects upon their involvement in decision making during the pregnancy and maternity care, the consumer does not consider it to be inclusive or view decision making to be representative of joint responsibility (let alone autonomy).

The findings suggest that clinicians either consciously or subconsciously manipulated the medical record’s record of events by implying that they shared decision making responsibility with consumers. I consider manipulated to be a justifiable term, because the Clinician Domain has shown that it is the clinician who takes primarily responsibility for decision making (although they do consider what is appropriate for the consumer) and therefore, their intentions to share decision making must be questionable. It is likely therefore, that consumer initiated requests for medical procedures in the medical record are a reflection of the clinician’s preferences. This indicates an absence of evidence of the consumer’s healthcare experience straying from the clinical document’s projected path; a path that medical experts determined to be appropriate.
Triangulation of the data highlights that despite overt evidence of information sharing, the decisions consumers are credited with making predominantly reflect clinician or organisational norms. This implies that clinicians use their technical expertise and authority in the guise of information sharing to manipulate women into requesting an ECS. Evidence of the reality of this asymmetry in clinical decision making is supported in both Australian (NHMRC 1996; Senate 1999; Appleton et al 2000) and international studies (Hopkins 2000). The unique finding from this study’s data is that the consumer is aware of this asymmetry.

The Mini Drama of Healthcare

In considering the significant findings that have been discussed up until now we may well ask, ‘why the charade’? Ignorance of the legal responsibility and professional accountability to keep ‘complete, chronological documentation of observations, interventions and outcomes’ (Wolff 1996) related to healthcare is widespread amongst the clinicians, so why then do they make a point of documenting consumer ‘requests’?

Bishop’s (1994) term mini drama was shown to be appropriate when describing the Environmental Domain findings. The Consumer Domain data contributes another dimension to the mini drama, in that whereas previously, it was considered that the drama was focussed on the struggle between the virtuous clinician and the powerful, imposing healthcare organisation, the triangulated data demonstrates that clinicians and consumers are playing out similar roles. However, the consumer is much more accommodating of the clinician’s dominance, and the clinician is more discrete in his/her expression of authority.

Further discussion of this finding is beyond the scope of this study. However, in building on from the consumer survey responses, I suggest, for future studies that intend to interpret consumer feedback, that consideration is made of the context of the consumer’s experience or his/her expectations as a prerequisite to any data analysis. Continuing to review consumer feedback in isolation from the context of their experiences, is likely to result in the consumer’s role in the drama being viewed as subservient but satisfied. Taking a multi-method triangulated approach demonstrates that consumers’ ratings are in fact an accurate reflection of
clinicians’ sub-optimal participative behaviours, and therefore a valuable contribution in efforts to improve healthcare quality.

**Consumer Outcome Measure**

In determining a consumer outcome measure, I seek to articulate consumers’ perceptions of their involvement in decision making in terms of satisfaction with that involvement. Satisfaction surveys are popular tools in healthcare research of this nature and consumer satisfaction measures are typically translated as being representative of healthcare quality. To calculate this measure it is usual practice to aggregate consumer ratings (AIHW 2000), and the literature asserts that a rating of strongly agree is representative of satisfaction (Brown & Lumley 1994; Turnbull et al 1999a). Therefore, to gain a measure of reliability, the same method of analysis is applied to the consumer responses in this study.

An aggregation of survey responses, across the three sites, identifies that between 55% and 65% of consumers strongly agree and therefore are satisfied with their involvement in pregnancy care decisions. In other words, at least 35% to 45% of consumers report their involvement in decision making as sub-optimal.

Quoting the consumers’ tendency to rate strongly agree for their satisfaction with full involvement in decision making; it can be said that the consumer’s sense of involvement in decision making is the result of active involvement in the information sharing and decision making attributes of their healthcare experience. However, when examining the consumer satisfaction data and its relationship to full involvement in decision making responses, I am unable to support such links. The analysis does highlight that consumer satisfaction ratings are not related to feeling fully involved in healthcare decisions; rather, it is whether the level of involvement per se, is to the consumer’s satisfaction. Some consumers express satisfaction with less than full involvement in decision making and yet some are not satisfied even though they perceive full involvement. These findings support my earlier concerns about the common practice of asking an individual consumer to interpret their healthcare experience and then combining this view with multiple other consumers’ views, as a means to generate a single measure. This practice does not value the voice of the individual and can be considered an
assumption, not unlike the clinicians own approaches to decision making [Domain Two].

A significant implication of the findings is that the link between expectations of involvement and satisfaction with involvement in decision making is obvious. In other words, no matter how competent or incompetent clinicians are at involving consumers in decision making, it appears that consumers will be satisfied with this behaviour if it reflects the level of involvement the consumer expects or wants. I acknowledge that to know what that optimum level of involvement may be for each consumer could not be determined by this study; however, the significance of this finding, strongly supports asking or clarifying with the consumers their expectations of the level of involvement in decision making now and in future satisfaction studies.

Consumer Satisfaction; an Inappropriate Measure of Healthcare Quality

This study demonstrates that because a consumer is satisfied with the level of healthcare involvement, this is not a reliable indicator of the quality of care received by the consumer or that the consumer was an active participant in their healthcare experience. Indeed, the data identifies that consumers are not measuring their level of satisfaction in relation to the quality of care received, but by their expectation of the care that they would receive, which in turn is moderated by their perception of what they could expect based on the organisational and clinician messages received. These findings contradict the AIHW (2000) endorsement of aggregated Commonwealth statistics that equate consumer satisfaction with the experience of a high standard of healthcare.

The finding that consumers do express satisfaction with less than optimal healthcare quality or outcomes, and that consumer dissatisfaction can be linked to inadequate or inappropriate clinical care processes, is supported by the concluding arguments of other research projects, including Kaplan et al (1989a), Cleary et al (1989) and Wilson et al (1996). They agree that a measure of dissatisfaction is potentially a more reliable outcome indicator or useful risk management tool than the satisfaction measure. However, as supported by this study’s data, one would still need to establish consumer expectations, because
consumers also claim to be dissatisfied with what is essentially optimal involvement in healthcare.

Unreliability of Aggregated Consumer Outcome Measures

A critical appraisal of the literature identifies a propensity for aggregated findings to misrepresent the views of the individuals within the group. This study’s findings demonstrate that there are multifactorial components to consumers’ healthcare experiences that do not justify using a one-dimensional measurement such as satisfaction as an outcome indicator. In addition, the findings also challenge the practice of aggregating consumers’ responses irrespective of the context of consumers’ healthcare experiences, prior to analysis.

The findings demonstrate the usefulness of a multi-method approach when seeking to collect reliable data to evaluate service provision or clinical practice. The findings also demonstrate an association between consumer dissatisfaction and a healthcare experience that has either inadequate or inappropriate clinical events occur or evidence of avoidable circumstances. Significantly, the triangulation shows a relationship between the consumer being dissatisfied with their healthcare and experiencing inconsistencies or mismatches between what they expected and the realities of their healthcare experience. Such events are also likely to adversely impact on the quality and safety of the consumer’s healthcare experience.

Mismatch between Consumers’ Expectation and Service Received

A serendipitous finding from the multi-method analysis of the consumer data, is that irrespective of the level of consumer participation activity/passivity experienced, consumers tend to rate their healthcare experience more favourably when they view that there is consistency between organisational philosophy, management structure and clinician practices.

This finding is also a feature of the Environmental Domain discussion, where Site B’s consumers were predominantly satisfied with their involvement in decision making, and yet there was an absence of evidence found in either the structure of the organisation, clinicians’ behaviours or the medical record to support the assertion that Site B’s consumers are active participants in healthcare decisions. Preference
for the paternalistic approach to decision making is consistent throughout consumers’ experiences. Therefore, consumers receive the consistent message that minimal involvement in decision making is expected and when minimal involvement is experienced, the consumer is satisfied with that level of involvement.

In contrast, Site A’s consumers are the least satisfied with their involvement in healthcare decision making. This finding is in contrast to the Environmental Domain that describes this site as having the greatest propensity for a participative orientation. However, Site A is also accredited with the greatest propensity for contradictory structures, behaviours and views; and it is these mixed messages that is likely to adversely influence consumer satisfaction ratings. Thus, the promise of a participative experience is not delivered. The triangulated data suggests that consumer dissatisfaction may also be compounded by an inconsistency in clinicians’ participative behaviours between the pre-admission period and the post-operative/discharge period. The medical record audit shows that any participation in care planning in the pre-operative period is not influential on consumers’ subsequent experiences, or is just ignored by clinicians. This may account for some consumers rating full involvement with pregnancy care decisions, yet being dissatisfied or perhaps frustrated with the lack of influence or respect paid to their contribution.

The unfavourable consumer ratings identified in this study, in association with a mismatch between what consumers actually expect from a service and the service that they receive has also been the outcome of a recently published study by McKinley and Roberts (2001) in the United Kingdom. Their study explores consumer satisfaction with an out of hours primary medical care model. Similar to the satisfaction ratings expressed in the present study’s consumer sample in regard to involvement in decision making, McKinley and Roberts assert that consumer satisfaction is not linked to the quality or structure of the service, but it is associated with consumers’ expectations of the services they would receive (2001). McKinley and Roberts’s findings support my argument that the mismatch between expectations and reality is multifactorial and thus requires a multi-method approach to address. Interventions are required that incorporate policy, procedure and organisation of clinical care features, as well as strategies for
communicating with consumers and clarifying their expectations, and then facilitating mutual consensus.

To achieve this transparency in expectation, I suggest that Adams et al’s (2001) simple recommendation be considered; that the most effective way of ascertaining a consumer’s expectation of the way healthcare is provided or the individual’s desire to be involved in healthcare decisions, is to ask them. In making an assumption based on this study’s data as to what it is that actually influences consumer satisfaction or positive health outcome measure; I assert that active involvement in healthcare decision making is a lesser priority to the consumer, than is consistency in the delivery of healthcare. It is also apparent that consumer satisfaction is not a proxy or reliable measure of the quality or safety of consumers’ healthcare experiences.

Summary of Domain Three Discussion

The findings show that these samples of consumers demonstrate a capacity to provide constructive and relevant feedback in regard to the environment and behaviours they experienced during their healthcare episodes. The findings also suggest that, despite the clinicians’ superficial attempts to conceal the fact, consumers are aware that clinicians prefer to give information than share decision making. Consumers are also aware that doctors are the least likely to share the responsibility of healthcare decision making and that communication barriers exist between clinical disciplines.

The consumer’s data suggests that consistency is more of a priority for the healthcare consumer than partnership in healthcare decision making. This means that irrespective of the level of participation activity/passivity, consumers tend to respond favourably to experiencing constant themes or messages between the views, behaviours and environment. The data also implies that consumers’ satisfaction with the level of involvement in decision making is relative to the level of respect paid to their contribution. Therefore, if consumers are offered or engaged in participative behaviours that are then taken away, manipulated or discounted, they are likely to be less satisfied than if they are never offered the opportunity to participate.
In essence, the findings suggest that consumers are prepared to play the role that has been cast for them in the *mini drama* that is healthcare, whether it is the engaging consumer or the passive patient. However, they are dissatisfied when the script changes mid-scene.

Limitations linked to aggregating and taking a one-dimensional approach to consumer satisfaction, have been acknowledged in the data discussion. In addition the findings also argue that consumer satisfaction is not necessarily an accurate indicator of the standard or quality of healthcare experiences. The findings suggest that numerous variables influence ratings of consumers’ satisfaction, whether it is with the level of involvement in decision making or other aspects of the consumers’ healthcare experience. When making recommendations on the basis of this study’s findings and in light of the literature, I suggest that a fundamental step is required to facilitate sharing the responsibility of healthcare by *sharing* involvement in decision making expectations (McKinley & Roberts 2001 and Adams et al 2001). This finding has implications for the culture, practice and documentation of healthcare.

The findings reinforce the value of healthcare organisations seeking out effective mechanisms to include consumers in the critical appraisal of healthcare delivery. Asking consumers what *their* expectations or needs of the service are in the formative stages (pre-admission) of their healthcare experience, *recording* and thus *communicating* these expectation/needs and finally, *evaluating* on discharge, whether *their* expectations/needs were met (or not), is a start.
Domain Four – The Medical Record

The primary objective of the Medical Record Domain is to determine whether the records sampled from each of the study’s sites can reliably indicate the level of consumer participation being practiced in the frontline of healthcare.

It was anticipated that the medical record audit findings from each site would vary and hence be unique to each site. However, this is found not to be the case. The data demonstrates that the frequency and distribution of participation indicators and evidence of participation is consistent in its inconsistency and absence across the sites.

The key findings include: the consistent absence of evidence of participation indicators in more than half of each site’s record sample; the prevalence of participation indicators in the pre-admission/operative episode of care in comparison to the post-operative and discharge episodes; and the superficial nature of the documented indicators when they are found.

Two independent audits (indicator and content) have been completed on the record samples. Due to the absence of comparable approaches to identifying participation indicators, I am unable to validate the indicator audit findings with current literature. The audit found the medical records to be predominantly incomplete, of poor quality, and task oriented. The reliability of this data is determined by comparing the findings with an independent coder using a validated screening tool (QaRNS Audit 2000).

As both the indicator and content audits are completed on the same sample of medical records, a comparison of the findings demonstrates that an absence of evidence of consumer participation indicators is unlikely to be due to an unreliable method. Rather, any absence of indicators is likely to be due to the overall poor quality of the medical records’ contents. Both the content and indicator audit findings imply that a relationship exists between the absence of consumer participation indicators and the incomplete content of the documents. This means the absence of evidence of collaboration between clinical disciplines by integrating documentation, the absence of critical documents (pre-operative documents, consent forms) in the record, and a haphazard record filing format are all related
to the *absence of evidence* of consumer participation indicators. In essence, both audits came to the same conclusions, but from different starting points. The following discussion examines the absence and presence of participation indicators separately and will be augmented with relevant findings from the environmental, clinician and consumer data.

**Participation Indicators: An Absence of Evidence**

An absence of evidence of consumer participation indicators in nearly 60% of the healthcare episodes audited across the three sites is one of the most important outcomes of this study. In other words, it is more likely that there is no indication (e.g. signing a prompt box) that the consumer has been involved in decision making and/or information sharing related to determining healthcare needs, than it is that such indicators are evident. Sites A and C have an absence of evidence of indicators in half of their healthcare episodes whereas Site B has an absence of evidence in two thirds of its healthcare episodes.

**Legal Implications of Findings**

There are potential legal implications associated with the audit findings from the medical record samples. The triangulated data suggests a correlation between the *absence of evidence* of consumer participation indicators in the medical record and the *evidence of absence* of consumer participation taking place during the healthcare experience. Jamieson (1999) states that in legal arenas, an *absence of evidence* of recording an event or action is equivalent to, *evidence of absence* or simply that the event did not happen. Using this description in the context of this study’s findings places individual clinicians who neglect to record consumer participation and organisations that do not facilitate action (i.e. clear documentation of the planning, processes and outcomes of clinical care), at risk of being found negligent in the event of a legal inquiry.

**Reliability of Indicator Audit findings**

The reliability of the findings of the records’ contents audit is considered valuable in determining the reliability of the participation indicator data. A comparison of
the audit findings supports the notion that the extensive evidence of absence (absent or incomplete content), is in fact a reflection of the overall poor quality of the medical records, and not merely the absence of participation indicators.

The contents audit demonstrates the records to be consistently incomplete. Deficient or absent documents, in particular risk management documents, raises concerns about the quality and safety of the healthcare provided at each site. The incomplete operative, anaesthetic and post-operative documents featured throughout the study, places the consumer at considerable risk. Unfortunately, the identification of these risky practices is not limited to the findings of this study, medical record audits in both Asia (Roach et al 1998) and the United Kingdom (Cowan 2000) have previously found considerable documentation deficiencies (60–70% documents incomplete) in surgical records.

The data demonstrates that although site-specific documents exist, each of the clinical disciplines (irrespective of site) show similar preferences for recording healthcare progress. For example: progress notes are the likely source of medical documentation; clinical pathways are the likely source of midwife documentation; and standardised surgical documents are where theatre nurses, anaesthetist and surgeons tend to document. In addition, clinicians report the preference for communicating healthcare progress face-to-face using opportunistic meetings with colleagues or consumers. The range of document preferences and the unpredictable nature of clinicians’ communication preferences across the sites explains the prevalence of incomplete documents. The significance of this data therefore, is that an absence of evidence of participation indicators in the medical record should not be unexpected. Yet this is still quite a surprising finding, given the litigious nature of contemporary healthcare, especially obstetrics.

Variations in clinician behaviours regarding communication of clinical care, coupled with the absence of evidence of a coordinated and collaborative approach to clinical care across the sites, is considered contributory to the evidence of absence of a participative approach to clinical care. A review of the literature supports the view that absences such as these in the healthcare setting, can be linked to evidence of: a reduced intention of healthcare providers cooperating with each other (Moorhead et al 1998; Degeling et al 2000); increased clinical errors (Parker &
Coiera 2000; Brown 2002); a discontinuity of care (Robinson & Compton 1997; Senate 1999); and an impediment to enabling consumer participation in healthcare design (Cabral 1997; Homer et al 1999). This study’s multi-method approach has facilitated the purposeful accumulation of evidence to support the existence (or propensity for) of each of these disruptive features in each of the study’s sites. The implications are discussed in detail in this chapter.

Documentation Omission and Adverse Healthcare Outcomes

The triangulated audit data demonstrates that documentation deficiencies, including incomplete and inadequate documentation, are widespread across the care continuum, as well as between and within clinical disciplines. Documentation deficiencies, such as those found using the QaRNS based content audit, have been associated with increasing the potential for a highly preventable injury or adverse event related to the consumer’s healthcare experience occurring (Wilson et al 1995). Significantly, an association exists between the omission of documentation in the medical record and the incidence of preventable adverse events.

Expanding further on Wilson et al’s (1995) study, using a retrospective medical record audit method, Wilson asserts that it is twice as likely that an individual would experience an adverse event related to an absence of evidence of decision making, than there were adverse events associated with documented evidence of decision making. The findings of this study support Wilson et al’s (1995) assertion, in that the absence of evidence of consumer participation indicators, or absence of any mechanism to communicate or actively engage consumers in their healthcare experience has raised numerous quality and safety issues. The implication of the similarities in this study’s findings and Wilson et al’s (1995) findings is evident in their closing arguments. They assert that clinicians’ practices are adversely influenced by the inadequacy of documentation available at the time of decision making, hence this inadequacy manifests into an increase in preventable human errors and a system that is not patient protective or resource efficient. This sequence of events also leaves the organisation and clinician open to litigation (Wilson et al 1995).

Triangulating the audit findings with the Environmental and Clinician Domain’s data demonstrates the prevalence of consistently incomplete documents being
representative of the questionable quality of the organisation of clinical care, as well as the views and behaviours of clinicians. In discussing each Domain’s data, the absence of evidence of a coordinated and collaborative approach to healthcare, clinicians’ intentional absence of recording or evaluating clinical care and a preference for opportunistic communication behaviours that do not require or result in the documentation of clinical care, are recurrent themes. These findings support the view that the absence of evidence of consumer participation indicators is an accurate reflection of the evidence of absence of either the environment or the clinicians, having the capacity or willingness to share the responsibility of healthcare with consumers. The implication of these findings is that it is likely that the sites are not aware that the way that clinical care is organised and practiced increases their vulnerability to litigation, resource wastage and risks clinical errors that are preventable. Alternatively, the sites may be aware but lack the capacity to address underlying organisational or clinical causes. In light of these implications, further detailed exploration of the link between adverse events and documentation omissions is beyond the scope of this study, yet warrants further research.

Putting the findings into Perspective

The significance of the data triangulation, is magnified when one considers that this study’s clinical procedure (ECS), is often referred to in the literature as a clinical scenario that follows a predictive path, where the environment is purposively designed and committed to supporting consumers in the determination of their own health management (NHMRC 1996; Quinlivan 1999; deCosta 2001). The findings do not support this perception. The high potential for litigation, associated with obstetrics is also considered adequate motivation for timely, accurate and comprehensive documentation of consumer involvement in decision making and information sharing throughout the healthcare trajectory (Roach et al 1998). Yet, the views and behaviours of the clinicians in this study suggests that they perceive themselves to be immune to (or ignorant of) the potential for litigation for not documenting their actions or the decision making pathway that lead to their actions.

This discussion is not aimed at discrediting the intentions of these organisations to facilitate continuity, safety and information sharing as key healthcare
attributes. However, the absence of evidence of compliance or personal belief in such attributes, by those responsible for enacting the attributes at the frontline of healthcare, is likely to have minimal influence on consumer health outcome measures (Patterson & Sinclair 2003). One strategy that has the potential to enable organisational goals to be reflected in clinicians’ views and health outcomes is to engage in an open, participative and progressive process of modifying the practice or values of clinicians, rather than modifying the process to suit the professional/organisational culture (Patterson & Sinclair 2003). However, if the level of consultation is at the same restricted or tokenistic level that consumer participation initiatives have been witnessed in this study, then it is likely that the strategy will have little impact on the quality or safety of healthcare.

The findings demonstrate that the absence of evidence of consumer participation indicators in around 60% of the healthcare episodes audited, reliably represents not only the social reality of consumers’ experiences, but also the reality of disrupted, ineffective, risky healthcare episodes. This finding supports Wilson et al (1995) finding that 52% of preventable adverse events are associated with the omission of documenting decision making processes.

In essence, the triangulated multi-method approach to this study has provided an insight into why the absence of evidence of consumer participation indicators is a reliable reflection of consumers’ healthcare experiences. Now, the challenge is to further understand the significance of the evidence of indicators in relation to the location in the healthcare trajectory, the intention and the effect they have on the consumer's healthcare trajectory.

**Participation Indicators: Significance of Presence**

Location of Indicators in the Healthcare Trajectory

The audit data shows evidence of consumer participation indicators to be a feature of documents that include: accessibility to the consumer; participation prompts for clinicians; and a multidisciplinary approach or division of clinical responsibility within the document. Documents with these features can be found in the pre-admission/operative episodes of care. An analysis of the data suggests
that these features combine to create a regulating effect on clinicians’ pre-admission/operative documenting behaviours. This argument is supported by the literature, where documents that incorporate standardised, integrated and participative elements have been associated with regulating clinicians’ communication and documenting behaviours (Driscoll & Caico 1996; Zwarenstein & Bryant 1998; Robinson and Compton 1997; Degeling et al 2000).

An interesting finding when comparing indicators of consumer involvement in decision making and information sharing with the standardised, integrated and participative elements of the records’ documents, is that post-operative and discharge documents demonstrated standardised elements, but tend not to be integrated; moreover, the participative elements are directive to the consumer, rather than overtly inviting participation. The absence of each of these elements is influential on the absence of evidence of consumer participation in the post-operative and discharge documents in relation to the pre-admission/operative documents. The implications of these findings is that the documents reflect the Environment and Clinician Domain’s findings, in that the orderly, coordinated approach of the pre-admission episode is replaced with the disruptive, discontinuity of clinical care in the post-operative/discharge episode. However, the post-operative/discharge documents can be considered regulatory because they sustain a profession based, medical approach to clinical care.

The insight provided by the triangulated data, enables me to recognise that the prevalence of consumer participation indicators associated with documented prompts in the preadmission/operative episode of care, is unlikely to be a reliable reflection of clinicians’ commitment to either healthcare quality (Adeyi & Morrow 1997), or providing continuity (Hofmeyr et al 1994; Hodnett 2002) in the consumers’ experiences. In examining the triangulated data, I cannot unequivocally determine why the preadmission/operative organisation of care and/or documents tend to represent a collaborative approach to healthcare, or why clinicians complete these documented prompts, whilst these approaches or behaviours are not reflected in the subsequent episodes of care.

In an attempt to find meaning in this paradox, I suggest that if clinicians view the participation indicator theme to be safe, then it is more likely to be documented in
the record. From the data, participation themes that are categorised as *safe*, are those aspects of care that are unlikely to require a re-organisation of pre-admission clinician practices (e.g. feeding preferences and discharge planning). The data demonstrates that clinicians are twice as likely to record a response to these questions as document the discussion of anaesthetic options. This implies that active involvement by the consumer in discussion on anaesthetic options may require a disruption to pre-admission processes and are therefore avoided. Furthermore, the pre-operative document prompts are also *safe*, because they are designed to seek information from the consumer, not to individualise the design of clinical care. To understand the prevalence of indicators in this episode of care, it is warranted to consider that the association between pre-operative care and litigation might also be high in the consciousness of clinicians and the organisations; hence, the motivation for indicating the consumers’ involvement might be to protect them from potential litigation.

It has been suggested that the findings present the preadmission/operative episode of care as the *window* of healthcare, and it is *dressed* strategically in participative intentions. Once beyond the *window*, the absence of organisational or clinicians’ intentions to adopt the consumer oriented model is *exposed*. This supports the use of Bastian’s *window dressing* (1994) to describe the lack of evidence of consumer participation in this study’s sites. An inability to sustain a participative environment beyond the pre-admission period is a descriptor that this study can add to Bastian’s definition of *restricted scope* consumer participation activity levels (1996). The lack of sustainability is compatible with the clinicians’ *tokenistic* sharing of the responsibility of healthcare by completing pre-admission participation prompts. This means that clinicians’ insight into the futility of attempting to sustain even a *token* level of participation beyond the pre-admission/operative episode, can account for why they abstain from documenting or indicating that they include or consult consumers in the ensuing episodes of care. In addition, the potential for litigation related to not consulting the consumer is less likely in the post-operative and discharge episodes of care.

Overall then, the findings support the view that the prevalence of consumer participation indicators in the pre-admission/operative episodes of care is associated with clinicians’ *tokenistic* completion of prompts in the medical record.
However, the absence of evidence of indicators beyond this episode of care, and the evidence of absence of the environment or clinicians being willing, or supported, to adopted a consumer orientated approach to healthcare, requires further examination. Further research is required to meaningfully understand the motivation behind the clinicians’ recording of consumer involvement in the pre-admission/operative episode of care.

**Participation Indicators: Intention and Effect**

Despite the presence of regulating attributes in the pre-admission/operative documents, and consequently the prevalence of overt and implied participation indicators in these episodes of healthcare, the audit findings also identify that the nature of consumer engagement, *only* reflects these prompts. As discussed previously, if a document directs clinicians to discuss *infant feeding preferences* or *expected length of hospital stay*, then documentation is likely to include consumers’ responses to these prompts. Even though participation such as this can be described as essentially superficial in nature, this still indicates that consumers are participating in their healthcare experience by sharing information, which could then be used to guide the provision of appropriate healthcare.

However, the findings demonstrate that consumer led information, gained in the preadmission/operative period is unlikely to: ever be referred to again; be the basis of care planning; or, used as a mechanism for reviewing consumer healthcare experiences. It is a recurrent finding that consumers’ response to pre admission/operative prompts, are not influential on their healthcare experience at all. The following is an example of the absence of evidence of participation by the consumer during the pre-admission influencing subsequent healthcare:

Pre-operative documentation states the woman expected a ‘repeat caesarean section’ and planned length of stay to be ‘three days’.

Post-operative documentation states, Day 2 Evening ‘the patient wishes to go home tomorrow’. The process of, arranging medical review and follow-up, commenced that evening of Day 2

Discharge documentation states Discharge delayed till the Evening of Day 3, ‘patient upset about delay’.
Thus, even when the consumer’s expectations of her healthcare experience is clearly stated in the record, it appears to have had little or no impact on what actually happens thereafter. This suggests that any evidence of involvement in healthcare decision making does not mean evidence of the consumer’s healthcare being influenced by such involvement.

The absence of evidence of consumers’ contributions being influential on their healthcare trajectory represents consumer marginalisation. The NRCCPH (2002) describe this as a mechanism commonly used in healthcare systems where consumer feedback is sought, but the information is not used to support, or implement modifications to service delivery or clinical practice. In addition, the absence of evidence of consumer initiated variations (eg. documentation of consumer special needs) being recorded, or variations in consumer healthcare outside of the projected trajectory, indicates that consumers are not considered equal, nor integral, in designing any aspect of their clinical healthcare experience.

By tracking consumers’ healthcare trajectories, the triangulated data confirms that consumer contributions are not the foundation, or driving influence for ongoing care design or evaluation, but rather consumers’ contributions are likely to reflect the cultural norms of the sites. Therefore, the anticipated participative nature that the documented indicators suggest, could not compete with an environment that is incapable of engaging, or supporting, an active level of consumer participation. In effect, there is an absence of evidence to indicate that consumers are approached as equals with different expertise (Coulter & Dunn 2002). Furthermore, data triangulation indicates that such absence of evidence reflects reality; meaningful consumer participation is not happening, even when they (consumers) are being consulted.

Documenting Consent: A Participation Indicator?

Another feature of the data triangulation is the clinicians’ preference for minimisation of documentation. Doctors in particular appear to use the medical record primarily to record evidence that consumers have been consulted in the decision making that precedes the consent required for an elective surgical procedure. Isolated statements such as, women requests, wants, or wishes an elective
caesarean section were frequently recorded in the preadmission/operative documents. For example:

‘Patient requests Trial of Scar, explanation to patient of risks of ruptured uterus, patient now wishes to have an elective caesarean section’ (Doctor)

The triangulated data supports the likelihood that doctors’ behaviours are motivated by legal obligations, rather than genuine participative intentions or wanting to accommodate the consumer. For example, the findings demonstrate: a preference amongst medical personnel for the paternalistic approach to decision making; clinicians self-report a lack of accountability to record or track variations in clinical practice; and, an absence of evidence of recording consumer participation indicators, once the consumer has formally consented for the procedure, or progressed past the pre-operative episode. Furthermore, the level of inclusion or discussion that is implied by the doctors record of events is contradicted by the consumers’ tending to rate doctors’ involvement of consumers in decision making as the least participative behaviour they experienced.

Rather than an indicator of the level of consumer inclusion, or shared responsibility in designing clinical care, the prevalence of doctor documented participation indicators implies a covert fear of litigation. This means that doctors' tendency to transcribe the process of obtaining informed consent, by indicating the consumers' active involvement in the process ('requested'), is a premeditated behaviour. This documenting behaviour is described by Cowan (2000) as a legacy of the medicolegal pressure placed on clinicians to document not only clinical events, but also the clinical decision making process that precedes the events. In this context, sharing the responsibility of healthcare could be interpreted as meaning the doctor is sharing his decision with the consumer, not involving the consumer in decision making. A consequence of this documenting behaviour is that the consumer is then responsible for sharing the outcomes of the doctors' decision. The implication of this practice deserves further research. Radcliffe (1999) for example, argues that rather than the focus of medical documentation being about responsibility of care, it is now about covering your back legally. Therefore, it could be argued that documented consumer involvement is a mechanism for shifting the medicolegal responsibility of
healthcare from the clinician/organisation to the consumer, whilst the decision making power remains with the clinician.

Establishing Roles in the Healthcare Partnership

The indicators of consumer involvement in decision making or information sharing that features in the data triangulation tends to be superficial in the preadmission/operative participation and then absent in the postoperative/discharge period. This is explained by the consumer in their initial healthcare interaction being acculturated to the level of participation expected or tolerated. When the consumer makes initial contact with the organisation or with healthcare providers, this interaction is known as the formative stages of the healthcare partnerships (Brown 1996, cited in VandeVusse 1999). The formative stage is characterised by the consumer establishing the practicalities or ground rules of the healthcare relationship. The findings demonstrate that the dynamics in this formative stage reflects the traditional medical approach, and a mismatch between the levels of participation that is offered and that which is available. These events influence a consumer’s interpretation of their role and are likely to minimise their sense of control over their healthcare experience (England & Evans 1992). These events are also likely to adversely influence the consumers’ sense of trust (Hopkins 2000) and/or their self determination (Lorig et al 1999). The consequence of these events is that the consumers’ self-efficacy in their capacity to contribute or influence problem solving and information sharing activities is likely to diminish in a cyclic mode. This means that as time and the healthcare trajectory progress, consumers sought to be less involved, resulting in an increasing absence of evidence of consumer participation.

The triangulated data clearly shows that the consumer is covertly exposed to the relevance (i.e. time, place, and purpose) of consumer participation in designing and evaluating healthcare. That time and place is prior to admission or surgery and the purpose is to allow clinicians to meet their legal documenting responsibilities and to inform consumers of the likely or preferred pathway their healthcare experience will follow. In other words, relevance means that at the commencement of the consumer’s healthcare trajectory, discussion and negotiation would be accommodated; however, once within the post-operative and discharge episodes, the processes are defined, directive and not conducive to further consumer
involvement. As discussed in the Consumer Domain, this scenario is representative of the power asymmetry associated with traditional healthcare relationships. In this situation consumers may comply, either because they wish to please and adopt a passive dependent role (Redfern 1996), or they may perceive that they are bullied (Rankin 2001) to comply with institutional norms.

This sequence of events is verified in the findings by the absence of evidence of consumers initiating, or contributing, to decision making or information sharing after their initial contact in the pre-operative episodes of care. This suggests that consumers’ preadmission/operative experiences may adversely influence any prior active intentions, or confidence they may have had in sharing the responsibility in healthcare decisions. Hence, consumers’ interpretation of their preceding experiences is likely to condition them to the role of passive participants or patients. This conditioning would further explain the absence of evidence of consumers participating in subsequent healthcare episodes (Kaplan, Greenfield & Ware 1989b; O’Connor et al 1999). The potential for conflict in expectations or role confusion, may also account for consumers’ varied perceptions of their involvement in decision making and their level of satisfaction with that involvement.

In essence, the triangulated data supports the Senate’s (1999) concerns that the level of participation reported is not representative of the level of participation practised. The Senate (1999) expressed concerns that features designed to facilitate participation in healthcare have been misappropriated into interventions that serve to assist clinicians and organisations to maintain the status quo of the medical model, avoid litigation, monitor healthcare complaints or demonstrate compliance with government recommendations. Covert manipulation of the consumers’ contribution to healthcare by both healthcare organisations and clinicians, when seeking to justify service or clinical outcomes, is an unverified strategy often raised in the literature (VandeVusse 1999; NHMRC 1996; Al-Mufti et al 1996; Appleton et al 2000).

In summary, the intentions and effect of the participation indicators identified in the medical record audit have been discussed. The triangulated data supports the notion that it is unlikely that the study’s sites or clinicians would be able to
sustain any level of participation beyond the preadmission/operative period. In addition, it is likely that indicators of participation, that are of superficial intent or token gestures, will have minimal impact on consumers’ healthcare experiences thereafter. It is likely that the concept of participation has been manipulated to meet the service and medicolegal needs of the organisation and clinicians. It is also likely, that consumers may react individually to the contradiction or façade that faces them (e.g. they may embrace the role offered to them or alternatively they may feel they are bullied into the role). Either way, they are likely to concede to a passive role by the time they reach the conclusion of their healthcare experience (discharge).

**Summary of Domain Four Discussion**

An absence of evidence of consumer participation indicators in most of the records in the study’s samples is a key finding for this Domain. The significance of this finding is that the triangulated data links the absence of evidence of participation indicators, with evidence of absence both in the contents of the medical record and in the context of the consumer’s healthcare experience (i.e. the environmental attributes, clinician’s behaviours and views, and consumer reflections). The study’s multi-method approach highlights evidence of absence of capacity, commitment, or consensus towards enabling an active level of consumer involvement in designing their healthcare. In other words, those who write in the medical record or provide care in the clinical environment are truthful in recording little or no activity in relation to consumer involvement in healthcare decision making.

Recurrent themes in the process of exploring what is significant about the consumer participation indicator findings include: the superficial nature of the participation indicators; the improbability that the indicators influence the consumer’s healthcare trajectory; and, that the indicators are nothing more than a token gesture, that fulfils medicolegal documentation requirements.

The association between healthcare participation strategies and the manipulation of the consumer is an aspect of the study that raises concern. The data identifies that an absence of a participative or consultative approach to healthcare is not only restricted to the consumer. Rather, restrictions and manipulations are
scattered throughout the structure and organisation of clinical care, the document design/format, and the views and behaviours of clinicians. The methods used in this study create a measure of transparency to some of the more restrictive attributes of healthcare; however, it has become increasingly apparent that the mismatch between intention and practice is transferable throughout the healthcare trajectory, and is likely to be a substantial barrier in determining the effect of healthcare participation strategies.

Other areas for further research that emerge from this Domain include the exploration of what motivates clinicians to record consumer involvement in the preadmission/operative episode, and the development of strategies to support, not only the communication of consumer documented expectations into the subsequent episodes of care, but also to use consumers’ expectations as a blueprint for their care trajectory.
Summary of Chapter Five Discussion

In this chapter the study’s findings have been discussed in the context of the literature review and recently published consumer participation studies. The findings demonstrate that it is an unwarranted expectation that the Australian healthcare community has the capacity, or is willing to orientate their services, or clinical practices, to accommodate the shared responsibility structure of the consumer oriented healthcare model.

The triangulated multi-method approach to this study’s data, demonstrates that the consumers are likely to be passive participants in their healthcare episodes. Commitment to the consumer oriented philosophy across the sites is likened to window dressing, where the participative attributes are described, rather than displayed in the structure, beliefs or behaviours of the organisation and clinicians. Considering the superficiality of this commitment, Bastian’s (1996) restricted scope is the descriptor that best explains the level of consumer participation activity evident within each site. The findings characterise consumer participation as passive rather than active. At the level of restricted scope, experts advocate on the behalf of consumers, be it in the organisation of care, clinical decisions or in prioritising the aspects of care that influence consumer outcome measures. This level of activity is also associated with token gestures.

Therefore, the data concludes that the absence of evidence of consumer participation indicators in the medical record is a reliable representation of evidence of absence of consumer involvement in care planning and decision making for the elective surgical procedure (ECS). The data triangulation contradicts earlier assertions that joint problem solving, joint decision making, and joint responsibility are attributes of the healthcare consumer’s experience in contemporary Australian healthcare settings (Consumers’ Health Forum of Australia 1990; cited in Bastian 1994). In effect, the findings suggest that an active level of consumer participation may not even be a priority of the consumer, and that further research is required into whether the push for an active level of participation is a consumer led initiative or experts speaking on behalf of the consumer.

Johnson & Bament’s (2002) form to follow function pathway has been useful in making sense of the study’s recurrent inconsistencies. This study’s findings
demonstrate that the function that the consumer participation philosophy is playing in the study’s sites has not been explored, nor has a participative approach been taken to appraise the environmental, professional or community’s capacity to adopt the values or skills required for such a significant change in culture. The absence of evidence of this pathway has affected the study’s sites by: minimising the organisation’s capacity to facilitate or sustain a collaborative or evaluative approach to healthcare; reducing clinician’s awareness of accountability or motivation to reorientate from the traditional self governing, paternalistic approach to healthcare; and, adversely impacting on the quality of healthcare.

To support the functionality of the consumer participation philosophy means adopting a collaborative and participative approach to developing infrastructure and facilitating transparency. Consequently, consensus within the organisational philosophy and structure, the workforce culture, and the community’s expectations is warranted. Adopting this approach will assist in addressing any inconsistencies and in developing appropriate mechanisms to measure the effectiveness of service delivery or clinical practice.

In addition, the data highlights that if it is the healthcare organisation’s objective to work in partnership with consumers, then the development of a supportive infrastructure should not be in isolation from the individual consumer. Although it should be expected that healthcare consumers form expectations prior to their healthcare experience, and clinicians in some cases record consumer expectations (e.g. length of stay), the findings suggest that this is a token concept and is not acknowledged as a practice that results in existing healthcare practices being disrupted. The findings recommend that strategies be introduced to:

- ascertain the level of participation activity expected or wanted by asking the consumer;
- consider each consumer’s expectations/feedback individually rather than collectively or as an aggregated measure
- negotiate with consumers
- work towards sustaining a standardised approach that reflects the mutually agreed healthcare trajectory
Finally the findings suggest that the acculturation of traditional structures, processes and roles related to healthcare is so deeply imbedded in the views and behaviours of individuals, that the mini drama of healthcare is a reality. This means that the inconsistencies and the lack of function are synonymous with healthcare, and that on every level guidance and support is required if traditional healthcare philosophies are to change.

The following and final chapter includes a critique of the study’s design, and will highlight the implications and recommendations related to research, education and practice that have emerged as the result of this study.
Chapter Six

CRITIQUE OF STUDY DESIGN, IMPLICATIONS OF FINDINGS AND AREAS FOR FURTHER INVESTIGATION

Introduction

This study examines the practice of consumer involvement in the frontline of healthcare. In particular the study’s methods extrapolate indicators that an individual’s healthcare experience is re-orienting towards joint responsibility or partnership between consumers, their multidisciplinary healthcare team and the healthcare service. The literature review highlights the complexity of seeking: to determine the level of participation activity; define specific healthcare attributes; or, link health outcomes with consumers actively participating in their healthcare experience. Indeed, at a local, national and international level there is an absence of consensus as to what is recognised as active participation at the individual level of healthcare. Therefore, rather than offer solutions, this study adds to the scarce research that is currently informing the consumer oriented healthcare debate.

The purpose of critiquing the study design in this concluding chapter is to allow for the implications of the study to be viewed within the context of its strengths and limitations. It is also important to remember that this study is nestled within a much larger project. This impacted on the study by allowing me to have access to the Commonwealth project’s resources and databases. Consideration of the size, scope and rigour of the Commonwealth project explains why I make, what may appear at times, to be strong assertions related to the study’s findings.

That the medical records’ content is representative of consumers’ participation in their healthcare experience is a significant finding from this study. In essence, this study’s multi-method triangulated data supports the assertion that the absence of evidence in the medical record, of individual consumers actively participating in information sharing and decision making, is a reliable
representation of evidence of absence, of active participation by the consumer in their healthcare experience.

The findings also demonstrate that across the study’s sites numerous dysfunctional attributes exist within the culture and practice of healthcare. Indeed, rather than the consumer participation philosophy being strategically integrated into the practice and delivery of healthcare, triangulation of the environmental, clinician, consumer and medical record data shows chaos, with obvious inconsistencies between government policy, service processes and individual’s practice and beliefs. These findings contradict the AIHW’s assertion in 2001 that the consumer oriented model is well on the way to being integrated Australia-wide into mainstream healthcare.

Following the critique of the study’s design, the recommendations from this study will be made. I consider this study to be a building block, which will make a significant contribution to the limited body of knowledge related to identifying and measuring attributes of the healthcare partnership that indicate that consumers are active participants in their healthcare experience.

Critique of Study Design

As stated previously, I was a member of an experienced and well resourced research team completing the second phase of a Commonwealth project (Sorensen et al 2001) during the completion of this study. The Commonwealth project’s methodology influenced the location of this study’s sites, the sample size, the sampling conditions, and facilitated gaining ethics approval. Being part of a sizeable study and research team has allowed me to explore the reliability and the significance of this study’s findings with the audit, interview data and observations collated by co-researchers or independent auditors within the same research population.

Reliability of Data Collection Tools

The data collection tools are a combination of those designed for the Commonwealth project and tools specifically developed or modified for this
study’s purposes. The tools designed for the Commonwealth project include the clinician and consumer survey (Degeling et al 2000), and the QaRNS audit screening criteria (ACSQHC 2000; Wilson et al 1995). The project’s tools are reported to be validated tools (Sorensen et al 2001). In the event that validated tools were not available to measure concepts relevant to the present study, I have developed or modified data collection tools. These include: the medical record participation indicator audit; consumer involvement/satisfaction survey questions; and the environmental walk through audit.

The likelihood of variations in the reliability and validity of each of the data collection tools may have implications for the credibility of this study’s findings. However, to compensate for the possibility of these limitations, a diverse range of sources and methods have been used to collate and compare the findings. Furthermore, with an absence of tools that can claim to reliably measure consumer participation in healthcare, and given that this is essentially an exploratory study, I have elected to use less reliable, subjective, but no less important sources (e.g. previous clinical experience; QaRNS audit training; academic supervisors’ guidance; and research team’s contribution) to develop and define appropriate indicator categories of partnership in healthcare decision making and information sharing. The data triangulation demonstrates that although the indicator categories used are basic, they are still representative of consumer involvement in healthcare experiences.

Generalising an Individual’s Experience

The Commonwealth project team employed an independent clinical reference group of opinion leaders to determine and agree upon an individual attribute, relevant to each consumer, which could adequately represent the level of consumer participation activity that is present. The clinical reference group did not reach consensus, and this lack of consensus is featured in the consumer participation literature review (McMillan 2001; Hibbert & Jewett 1996). Therefore, I predicted at the onset of the study, that any attempt to
generalise consumer participation experienced at the individual level of healthcare, is unlikely to be reliable.

To address the implications of a lack of consensus about what determines consumer involvement in healthcare, the triangulated data is designed to draw out individual aspects of consumer experiences, whilst also providing an overall assessment. The triangulated data demonstrates that consumers may experience a range of participative attributes within each of the study’s Domains. However, the overall level of participation activity is likely to be restricted to a passive level of consumer involvement. It is a recommendation of this study that the following attributes are likely to influence the level of activity or passivity each consumer experiences and should be considered in designing future healthcare research:

- environmental attributes specific to each healthcare episode
- individual healthcare providers’ beliefs and behaviours
- consumers’ perception of their capacity or ability to sustain the level of participation activity they desire

Therefore, rather than determining an indicator of individual consumer participation activity or consensus on healthcare attributes that can be generalised, the data acknowledges the multifaceted attributes of consumer experiences. As has been demonstrated in this study, it is recommended that rather than attempting to isolate or to reach consensus as to one single measure of participation, efforts be made to collectively group the influential aspects of consumers’ healthcare experiences into Domains. These Domains would then be triangulated, examining the data for their individual and their overall influence on consumers’ experiences.

Reliability of Consumer Satisfaction Surveys

Claiming consumer satisfaction through an aggregated consumer health outcome measure has been demonstrated in the literature review to be a reasonably common and widespread association (AIHW 2000; Turnbull et al
1999a; Brown & Lumley 1994). Therefore, in this study I requested the participating consumers to rate their satisfaction, with their level of involvement in decision making, and then compared that satisfaction rating, with consumer estimations of the level of involvement actually experienced. However, in completing this study, I question the validity of aggregating consumer satisfaction ratings, or the reliability of consumer satisfaction with the level of involvement in decision making, correlating with an active level of involvement in healthcare decisions. It is a recommendation of this study that any future analysis of consumer satisfaction data is unreliable without first accessing data that clearly states the consumers’ expectations.

The findings demonstrate no links between consumer satisfaction ratings and how active/passive the consumer viewed their involvement in decision making to be. This relationship was determined by comparing how involved the woman felt with decision making in comparison with how satisfied she was with that level of involvement. In this study consumer expectations had not been collated and this is an obvious limitation of the study’s methods, but is also a significant finding.

It is a recommendation of this study that the use of one-dimensional consumer satisfaction data as an indicator of consumer healthcare experiences be reconsidered. It is not suggested that there is no place for the collection and analysis of consumer satisfaction data in healthcare, rather that the data is contextualised with consumer expectations. In addition, the triangulated data recommends that the practice of aggregating consumer responses, as a means of providing an overall rating of a healthcare service, process or attributes, be discontinued and efforts made to determine methods of preserving the individual consumer’s response, so that the validity and reliability of the measure is present.

In summary, the findings recommend that to gain a greater understanding of the level of involvement in decision making experienced, a prospective consumer interview or survey to gain baseline data on what consumers expected from their healthcare experience, will provide a valuable measure by
which to compare follow-up survey responses. To improve response rates from consumer samples in future studies it is recommended that the purpose of the study is introduced to the consumer during their healthcare experience, this will provide an opportunity to clarify their contribution to the study and their mailing/contact details for follow-up surveys.

Representativeness of the Clinician Sample

The usefulness of the contents of the medical record to inform the clinician sample has its strengths and limitations. The sampling approach (detailed p.118) was designed to assist the project team to make sure the clinician sample was proportionally representative of the frequency and distribution of nursing and medical disciplines identified in the contents of each site’s medical record sample. This approach to sampling was used by Degeling in 1998 and 2000 in related projects, and is considered reliable in providing the statistical tests and significance levels used to describe the strength of a relationship or difference, rather than as a basis of an inference to a larger population. This method of sampling limits the ability to generalise that this study’s clinician data is representative of the generic healthcare workforce. However, despite this shortcoming, the fact that the clinicians surveyed are directly linked to documentation in the consumer’s medical record strengthens the assertion that the views and behaviours of the clinicians surveyed are likely to have influenced the consumer’s healthcare experience in some form.

Across the three sites, the medical record’s audit of clinician signatures, identify on average, a total of 227 clinician signatures in each site’s record sample, with on average thirty-five of these clinicians, participating in the study. A limitation of this method is that the clinicians, who volunteered to participate in the study, may not hold the same views and behaviours or have been as influential on the consumer’s healthcare experience, as those clinicians who did not participate. Inviting only clinicians who have documented in the medical record may also mean that clinicians, who provide clinical care and yet do not contribute to the record contents, are excluded from the study. Despite sampling limitations, the triangulated findings demonstrate a
relationship between the views and behaviours of the clinicians surveyed and the contents of the medical record with the consumers’ views on their healthcare experience. Furthermore, the clinician demographic data within and across the three sites are remarkably similar. This finding demonstrates that by including a larger clinician sample, clinician behaviour trends are likely to follow the same trend. Therefore, rather than limiting the implications of the study, I suggest that a larger sample is likely to have reinforced the findings.

A conclusion that emerges from the findings is that the participating clinicians do not identify themselves as being capable of supporting an active level of consumer involvement. Furthermore, the data infers that the clinicians are not oriented to reflecting on, and assessing the participative attributes of their clinical practice. To gain a more meaningful understanding of the individual clinician’s views and behaviours towards consumer involvement, a recommendation from this study is that clinicians are asked either by survey or focus group to identify and define the key participation attributes within their clinical practice. This data would be useful in enabling the development of survey tools that reflects the clinician’s interpretations and practice of consumer participation in healthcare. It is a recommendation of this study that rather than concentrating on improving the sampling, consumers could be asked to provide feedback on what the clinicians identified to be their participative attributes. As well as feeding this data back to individual clinicians, it is recommended that the meaning and impact of this data on the clinician’s daily practice is captured by survey, audit and observation methods. It is also a recommendation of this study that the practice of aggregating clinician responses, as a means of providing an overall rating of behaviour, view or attribute, be discontinued. Instead, efforts should be made to determine methods of preserving individual clinician’s responses, so that the validity and reliability of the measure is present. This approach addresses the study’s finding that discipline specific issues need to be addressed, as well as generic deficits, before any change in the workplace culture could be expected. This has implications not only for research, but also those responsible for customising and implementing educational strategies or for strategically planning a reorientation of health service delivery.
Representativeness of the Consumer Sample

Inclusion in the consumer sample was predetermined by inclusion in the study’s medical record sample. A comparison between the consumers’ reported demographics and the demographics collated from the contents of the medical record demonstrate that each demographic variable is represented by consumers who completed the survey. There is however a discrepancy in that the medical records’ demographics indicates the samples as primarily multiparous women within the age bracket of 25-34 years, whilst the consumer’s survey indicates the samples as primarily primiparous women and within the 18-24 years age bracket. This discrepancy in the data is similar to the demographic data of Phase One of the Commonwealth project (Degeling et al 2000).

The prevalence for young primiparous women to respond, suggests that being a retrospective survey, completed at home, primiparous women may have been more likely to be motivated to complete the survey. It also suggests that the younger woman is more likely to either, feel they were capable of, or entitled to critically appraise their healthcare experience. The younger woman may also consider that providing feedback may favourably influence their subsequent healthcare experiences. Conversely, it also suggests that those consumers who have used the service previously (multiparous women) may consider that their feedback is unlikely to make a difference, or it may merely be that participating in the survey is not a priority for them. The implications for future research, is to further explore methods that would attract a wider range of healthcare consumer involvement in reviewing their individual experiences and the delivery of healthcare. By gaining this, the researcher would then be able to explore in detail, why consumers choose to be, or not to be, involved in healthcare surveys, and whether this decision is related to their age, parity, previous experiences, priorities, financial, educational, cultural, insurance status or whether they are simply just not interested.
Summary of Study Design Critique

On reflection, I consider that given: the level of knowledge available on individual consumer participation in healthcare design on either the organisational, clinician and community level; the exploratory nature of the study; and, the Commonwealth projects’ influence on the methods used; the approach to the study’s aim was appropriate for its time. I also consider that I would approach consumer sampling differently next time and that the study’s findings are appropriate building blocks for further research.

Implications of Study Findings

Learning from the experiences of previous researchers, that if the intention is to capture the complex and diverse issues that impact on the practice of consumer participation in the frontline of healthcare, then a *multifaceted* triangulated approach is overwhelmingly supported (Mead & Bower 2000; Wilson et al 1995; McKenna 1995; Cowan 2000). However, in taking this approach to the study a multitude of significant findings have emerged, both clarifying and confusing, as to why consumer participation is or is not evident in the frontline of healthcare. Deciding how to manage the number of findings and comment on them without losing their significance has been a challenge to me. Therefore, in a continuation of the way I have organised this study, the findings will be presented in themes, including their implications and recommendations for further exploration.

Evidence of Absence of a Participative Debate

Findings confirm the *evidence of absence* of a collaborative or participative approach to care in relation to the *function* of consumer participation beyond the organisational policy or service delivery level. This demonstrates an *absence of evidence* of any integration of the consumer oriented model beyond the policy level, to the frontline of healthcare in the study’s sites.

The *absence of evidence* of clinicians or consumers holding views, or claiming experiences, that are consistent with the consumer oriented model, implies an
absence of open discussion, or collaborative deliberation at the frontline. Not surprisingly, these inconsistencies hinder the implementation of the consumer oriented model; however, the hindrances are but symptoms, with the cause being an absence of evidence of clinicians or consumers attaching importance to active involvement in healthcare. In the study’s sites, it is apparent that the function of consumer participation in healthcare is considered a given, with an absence of importance being placed upon clarifying the rewards and losses associated with forgoing the traditional model, and adopting the consumer oriented model.

The provision for debate, deliberation and clarification of the intended function of the consumer oriented philosophy within the healthcare setting is a fundamental step in ensuring that the philosophy of the service, and therefore the framework in which healthcare is organised, and practiced, is compatible with the needs and beliefs of the community, the workforce and administration bodies. Hence, the first recommendation from this study is that before even considering the adoption of the consumer oriented model into a healthcare site’s philosophy, the function of such a model needs to be debated by all stakeholders. This debate may take place in open forums, focus groups or individual discussions. However, a prerequisite for such debate, as discussed below, is open discussion in a common language.

**Absence of Evidence of a Language that Reflects Consumer Participation**

The absence of evidence of identification with the consumer oriented philosophy to healthcare, beyond the occasional preadmission/operative indicator, is confirmed by the evidence of absence of consensus or dialogue as to ‘what is consumer participation in healthcare’? The implications of not being clear about how to express consumer participation either verbally, written or in actions must certainly be a hindrance in initiating or communicating any intended strategies. It is apparent that clinicians in this study knew how to communicate the clinical aspects of healthcare (ineffective as it is shown to be). It is also apparent that beyond completing the prompts in the documents, or indicating that the consumer requested surgery for medicolegal purposes,
clinicians are actually incapable (or ignorant) of any further purpose for communicating consumer involvement in healthcare.

The findings demonstrate that the clinicians surveyed lack a dialogue that reflects consumer participation. The absence of this dialogue has a compounding influence, in that it not only impedes any documented evidence of consumer involvement in healthcare, but also means that clinicians lack a method of exchanging ideas or of introducing participative attributes into their professional conversations. In turn, this finding reflects the absence of participative attributes in the preformatted documents of each organisation and in the review or organisation of clinical care across the study's sites. Furthermore, the clinicians demonstrate a preference for traditional, discipline specific communication methods. The implication of this is that clinicians are unlikely to initiate or engage in a discourse that reflects the consumer oriented philosophy without guidance or direction as to its significance or relevance to their traditional practices.

Hence the second recommendation from this study is essentially a prerequisite to the first. In order for the healthcare workforce to participate in the consumer oriented philosophy debate on policy, service and clinical practice levels, they must first be familiar with ‘what is consumer participation in healthcare’? This recommendation has both educational, practice and research implications. This also supports the earlier recommendation of asking clinicians to identify the participative attributes of their current practice and to clarify their understanding of what consumer participation means to them. This information can be useful in identifying knowledge or skill deficits and as a baseline for feedback either from consumers, colleagues or managers.

Restricting the Consumer to a Passive Level of Involvement

The relationship between the study’s four Domains highlights recurrent inconsistencies and mixed messages between healthcare organisations, professionals, and consumers. Discontinuity of care and a restricted (passive) level of consumer participation activity are features of such inconsistencies. One of the reasons behind the inconsistencies is the evidence of absence of
consumers' ownership of strategies intended to activate their participation across the sites. In effect, consumer needs were defined and voiced by experts; hence, it is likely that any strategies intended to meet consumers' presumed needs, are either inappropriate, or token gestures that frustrate the consumer (e.g. inquiring about the consumer's discharge plan at pre-admission, then disregarding it). The findings once again imply that neither the consumer, nor the clinician is familiar with the function that the consumer oriented philosophy plays in the healthcare experience. Therefore, each individual (consumer or clinician) interprets the intentions of the consumer participation strategies, within their own conceptual framework, placing meaning and values to words and actions that are unlikely to be replicated by the next person. In this scenario, the recurrent inconsistency experienced by the consumer, restricts their involvement to a passive level not only within each healthcare episode, but also with each interaction they experience.

This study's third recommendation builds on from the earlier two recommendations. This recommendation reinforces the importance of developing a dialogue that facilitates the conversation about consumer participation, and the need to then initiate a collaborative debate on the intended function of the consumer oriented model. This recommendation emphasises the need for consumers to not only be appropriately represented in the debate, but that the consumers actively participate in the debate. To do this, consideration has to be made about how to enable active consumer involvement in every policy, service and practice in healthcare so that participative initiatives are considered for their relevance to the consumer. Furthermore, the practicalities and accountabilities for enacting these initiatives need to be openly deliberated so that consumers and clinicians are involved in their continuous evaluations. To accomplish this, an action research methodology is recommended.

Absence of Evidence of a Sense of Accountability

The data triangulation contests the legal and ethical influence that social and regulatory policy is supposed to have on the views or behaviours of the
healthcare professional. Across the study’s sites, the absence of a sense of accountability to provide a safe environment, or meet legal documenting requirements is particularly obvious in clinicians’ documenting behaviours and the QaRNS medical records’ content audit. Moreover, there is evidence of a lack of commitment (or tolerance) for a collaborative and communicative approach to clinical decision making. The legal and professional implication of such findings is that the documentation practices by clinicians are not equivalent to the level of accountability for safety and standards that is an essential component of their professional registration.

In this study, conjecture is made as to why clinicians lack a sense of accountability for the quality of their documentation. The recommendation is made that their views on accountability and documentation are priority areas for further investigation. It is also recommended that in the annual performance review of all clinicians that documentation is a mandatory aspect of practice reviews so that the responsibilities and consequences are clearly demonstrated as to the expectations of best practice. In addition, scheduling into mandatory training requirements regular and appropriate educational activities that focus on professional responsibilities and legal ramifications of inadequate documentation practices is recommended.

The absence of evidence of accountability to document by the clinicians surveyed is not linked to the level of education, how recent qualifications were attained, or to any one clinical discipline (although doctors tend to demonstrate less accountability in their documentation views/behaviours than nurses/midwives). This finding suggests that it is unlikely that further intensive education in an academic curriculum for healthcare disciplines will have a significant influence on the documenting practices by clinicians in the workplace. Rather, the findings reinforce my earlier recommendation to ensure all disciplines provide evidence that they are aware of, and meet the documentation requirements within the clinical setting. Another challenge for educators and researchers is to explore methods of monitoring the practice of documentation by clinicians and swiftly identifying and addressing any inadequacies.
The findings show a tendency for inadequate documentation not to be isolated to a specific discipline or procedure; it is therefore obvious that the consequence of poor or inadequate documentation is minimal. The findings suggest that any disciplinary action by employing organisations, professional registration boards or by legal inquiry, related to inadequate documentation has been either successfully avoided, not imposed or ineffective in changing clinicians’ practices. The findings also imply that each site’s methods of ensuring or monitoring the safety and quality of their healthcare delivery are ineffective, and that they are also at risk of litigation.

The study’s fourth recommendation is that further exploration is undertaken at the organisational level into the methods used, or importance placed on, monitoring the adequacy of documentation and evaluating its impact on the effectiveness and safety of healthcare delivery. This recommendation includes reviewing the current methods of appraising the professional conduct of employees and by the individual professional bodies.

**Evidence of Absence of Preparedness for Change**

The findings demonstrate an absence of evidence to support the assertion that shared responsibility is the focus of each site’s approach to healthcare decision making. Moreover, there is evidence of absence across the sites to suggest that the environment and/or clinicians are even considering taking a different approach to decision making or reconsidering the patient as an individual healthcare consumer. The triangulated findings demonstrate that apart from superficial indicators of clinicians sharing decision making responsibilities (predominantly evident in the documentation of the consumer ‘requesting’ an elective caesarean section), consumers are passive participants in information and decision sharing activities. This level of participation activity reliably represents each site’s environmental capacity, but does not necessarily reflect the level of involvement expected by consumers or the level of consumer involvement each site’s philosophy or policies projects.

Across the study’s sites, the structure, organisation of clinical care and clinicians’ preferences for a paternalistic approach to decision making, are
consistently indicative of the traditional discipline specific medical model of healthcare. These findings encourage conjecture as to why the environmental attributes and clinicians’ views and behaviours openly contradict any suggestion of progressing towards the consumer oriented philosophy. One argument is that the beliefs and behaviours of clinicians are not intentionally opposing the joint responsibility policy and documents; rather, their approach to healthcare decision making is subconsciously regulated by values of the social culture that supports the medical hegemony of traditional healthcare. The opposing view is that clinicians intentionally manipulate the consumer and the healthcare system. Either way, the findings suggest that the traditional medical approach to healthcare is the model by which healthcare is currently structured. Furthermore, reorienting the patient’s role towards the consumer philosophy of equal partners with different expertise approach to healthcare decision making is not compatible with the existing model.

In addition, the triangulated consumer data highlights that being a partner, and sharing the responsibility of healthcare, is of less importance to the consumer than experiencing consistency and having shared understanding of the level of involvement in decision making on offer. In this study, providing the consumer with a consistent approach to decision making has a more favourable influence on consumers’ reflections or outcome measures. This suggests that consumers’ initial priority in defining their role in the healthcare partnership is simply a need to commence the relationship on equal ground, with shared understanding.

A key finding of this study is that the progression from a patient to a healthcare consumer is not only absent in the structure or organisation of care across the sites, but is not evident in the beliefs or consciousness of those clinicians participating in this study.

The findings indicate that the contemporary consumer role in healthcare is not that dissimilar to the traditional sick or patient role. It suggests that all participants of the healthcare community are currently either incapable or unwilling to challenge the traditional foundation of their own healthcare roles,
let alone able to advocate or model the shared responsibility structure that is purported to be the basis of the contemporary healthcare relationship.

As quoted in the study’s introduction, Patient is defined in The Macquarie Dictionary (1987) as either, ‘one who is under medical or surgical treatment’, ‘quietly persevering or enduring strain’, or ‘tolerant’. Furthermore, in Latin, patient, which is the origin of the word patient, means ‘to be passive’. A significant personal outcome is that I believed at the outset of this study that referring to the recipients of healthcare as consumers, was an appropriate terminology reflective of contemporary healthcare; however, my beliefs have been challenged. The findings demonstrate that the continued existence of a medical hegemony in healthcare and the traditional social attributes of the healthcare patient, described by Irvine (1999) as ‘conforming, co-operating and not interrupting healthcare routine’, is a recurring attribute that represents the consumers’ role in their healthcare relationship and their experiences across the study’s sites. For these reasons, I am reconsidering referring to those individuals whose healthcare experiences were integral to this study, as healthcare consumers. I now believe that patient may after all be the more appropriate title.

The findings suggest that neither organisations, clinicians nor consumers consider sharing the responsibility of healthcare decision making as a priority area that they are ready to address. Therefore, the fifth recommendation is that all participants of the healthcare community critically reflect upon the current model of healthcare, raising consciousness as to what their current role in the healthcare partnership is and what their expectations are in relation to sharing involvement in decision making. A participative debate of the function of the consumer oriented philosophy, this study’s first recommendation, is unlikely to have any impact on the status quo if no one considers that the reorientation of healthcare roles or sharing decision making is a priority. It is therefore recommended that the process of participative debate be pre-empted by identifying common ground that reflects the values of the healthcare community.
In actioning this recommendation, the findings suggest that opportunities are explored to facilitate consumers voicing their individual expectations of involvement in information and decision sharing activities. In addition, the consumers’ expectations are recorded, negotiated within the capabilities of the organisation and the clinicians, and then used as the basis of consumer evaluation of both the healthcare experience and the organisation’s capacity to meet consumer expectations. In following this sequence, it is hoped that the medical hegemony that persists in the subconscious of the healthcare community will be realised. Moreover, a dialogue that represents consumers’ interpretations of involvement in healthcare, rather than experts’ interpretations, will emerge. With this dialogue, it is likely that consumer expectations will be consciously considered a component of healthcare; it is also likely that a collaborative debate will result in defining a philosophy that reflects consumer priorities, rather than that of the experts.

**Medical Record Audit Represents Consumer Involvement**

The findings represent the experience of healthcare, for the well, young consumer within the study’s sites as being inconsistent and unpredictable, rather than the positive and reliable progression that the literature associates with ECS and the maternity care setting. Across the sites, the mandated introduction of the consumer oriented model of care has been demonstrated as having made little impact on the organisation or practice of clinical care. The data triangulation shows that introductory strategies that are evident within the sites are either tokenistic, open to manipulation, or incompatible with the workplace culture, clinicians’ beliefs or consumers’ priorities.

Given the assertion that the medical records’ contents are a reliable representation of the level of consumers’ involvement in healthcare decision making and information sharing, it would be remiss not to illustrate the relationships between the records’ audit findings and the environmental, clinician and consumer Domains’ key findings (Table 6.1).
Table 6.1 Relationship between medical record data and the study’s other Domains

<table>
<thead>
<tr>
<th>Environment, Clinician and Consumer Domain data</th>
<th>Themes</th>
<th>Medical Record Audit data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participative intentions are described in policy rather than displayed in the organisation or practice of healthcare</td>
<td>Window dressing</td>
<td>Single discipline documents that compartmentalised clinical care</td>
</tr>
<tr>
<td>Traditional models and views of service delivery: *Cost focused outcomes *Experts speaking on behalf of consumers</td>
<td>Restricted scope</td>
<td>Paternalistic inclusion in decision making – ‘safe options’ – document format reflects medical model of decision making</td>
</tr>
<tr>
<td>Inclusive gestures not matched by intention or action - mismatch</td>
<td>Token gestures</td>
<td>Token references to consumer involvement that is not followed up in care planning</td>
</tr>
<tr>
<td>Consumers are an information source that require education</td>
<td>Passive participants</td>
<td>Minimal evidence of the consumer influencing the standardised clinical pathway or evaluating care</td>
</tr>
<tr>
<td>Minimal professional accountability or practice regulation. Preference for unreliable methods of communication</td>
<td>Adverse impact on healthcare quality &amp; safety</td>
<td>Inconsistently complete or absent clinical documents</td>
</tr>
</tbody>
</table>

Table 6.1 shows that the medical record audit data is capable of providing meaningful data that is reflective of the consumer’s experience, the clinician’s views and behaviours, and an environment’s orientation. The medical record is readily accessible and accessed regularly as a source of healthcare data and is shown in this study to be a reliable source of indicators of consumer involvement in information sharing and decision making initiatives. Hence, it is the sixth recommendation of this study, that a medical record audit be considered as an initial step in determining the level of consumer involvement in healthcare for a specific condition within a defined site.

Table 6.1 also clearly demonstrates the relationships that coexist between the study’s Domains, and reveals the multiple layers of influence within the consumer/clinician relationship. This study has alluded to the complexities of
the individuals within the healthcare relationships and the impact of the environmental and cultural contexts in which such a relationship is enacted. It is therefore also a recommendation of this study that if the intention is to understand the experiences of either the consumer or the clinician in the healthcare relationship and the impact of the environment on their interactions, that in future studies a *triangulated approach* is taken; with the medical record being considered a reliable data source and contributing to the inquiry.

**Areas for Further Investigation**

Having presented the study's implications and recommendations, it is apparent that *real* participation is not just about *joint responsibility* in decision making, but is about *sharing* a generic collaborative and participative culture within healthcare. The key recommendations for consideration in future research have been extrapolated from the chapter and are detailed below:

**Methodological Considerations**

**Capturing Consumer Involvement in Healthcare**

This study identifies the following attributes as being influential on the level of activity or passivity each consumer experiences and it is recommended that they be considered in designing future healthcare research:

- environmental attributes specific to each healthcare episode
- individual healthcare provider’s beliefs and behaviours
- consumer perception of their capacity or ability to sustain the level of participation activity they desire

A further recommendation is that the data be examined for its individual and overall influence on the consumers’ healthcare experience using a triangulated methodology.
Determining Consumer Satisfaction

This study has argued that, the use of one-dimensional consumer satisfaction data and the practice of aggregating consumer responses be discontinued. If the intention of future research is to determine consumer satisfaction with the level of involvement in decision making, a prospective consumer interview or survey to gain baseline data on what they expected from their healthcare experience is recommended. An examination of each consumer’s expectation of involvement and then their satisfaction with that involvement is suggested as it provides context to the satisfaction measure.

Making Participation in Research Attractive to Consumers

To improve consumer involvement in research, it is a recommendation of this study that the purpose of any proposed study is introduced to the consumer prior to or at the beginning of their healthcare experience. This is an opportunity to clarify their contribution to the study, as well as their mailing/contact details for follow-up surveys. Researchers need to consider why consumers choose to be involved or not, in healthcare surveys in a particular community. Consideration of these issues or asking the consumer how the process could be made more attractive to them is likely to favourably influence participation in future research activities.

Determining Clinicians Views and Behaviours towards Consumer Involvement

In order to improve the appropriateness of the study’s design and facilitate data analysis it is recommendation of this study that clinicians be asked, either by survey or focus groups to identify and define the key participation attributes within their clinical practice. These definitions will guide the design process and they will also ensure that data feedback is relevant to the clinicians’ practices. It is also recommended that a multi-method triangulated approach is used to capture consumer involvement in clinicians’ daily practices, such as self-report surveys, medical record audits, consumer feedback and independent observation methods.
It is also recommended to reconsider only analysing aggregated clinician data as a proxy workforce measure, as this study has demonstrated the presence of individual, discipline specific and generic issues related to consumer involvement in healthcare that would not have been noticed if the clinician data was aggregated.

**Change Management Considerations**

The findings highlight the mismanagement of the reorientation of healthcare policy, service delivery and practices from the traditional autonomous model of provider centred healthcare towards the shared responsibility model of the consumer centred philosophy. A number of recommendations from this study are related to the fundamentals of change management such as raising awareness, stimulating appreciation, building capacity and enabling implementation of change to be responsive through systematic meaningful evaluation strategies being in place. Below I have summarised the recommendations that I believe will provide a clearer vision for strategically planning the way forward:

- The findings have featured an absence of a purpose for change within each Domain, and it is recommended that Johnson and Bament’s (2002) form to follow function pathway is a useful framework to consider when planning changes in healthcare. It is recommended that implementation of this framework is enabled by facilitating critical reflection on the participative features of the existing model of healthcare. This will provide an insight into the current context of healthcare relationships. Context is necessary in order for a meaningful debate of the function, purpose, responsibilities, and the motivation for challenging the status quo of the traditional healthcare relationships.

- It is obvious that the views and behaviours of the healthcare provider/clinician are integral to the effectiveness of any change strategies. This study calls for further investigation as to what clinicians understand consumer participation to be, its function,
purpose and how they communicate its practice to healthcare colleagues. This data could then be useful in: planning educational sessions that stimulate appreciation of the participative attributes of their practice; formatting clinical documents and preparing information documents for consumers that demonstrate the participative attributes; and, coaching consumers and clinicians in how to provide or seek meaningful feedback that will influence the participativeness of clinical practice.

The consumer is integral to the reorientation of healthcare; however, this study has shown an absence either of consideration of the consumer as a valuable resource, or attempts being made to determine the consumer’s willingness or ability to engage in initiatives intended to actively increase involvement in healthcare. The inconsistencies between how consumer participation is practiced in this study are both a positive and a negative finding, in that the consumer oriented model of healthcare is unlikely to be standardised. It is a recommendation of this study that future studies investigate what the consumer understands involvement in decision making to mean, what the barriers are to active involvement and ways to develop consumers’ competence in sharing this information with their healthcare provider.

**Governance Considerations**

Governance is a framework for enabling quality and accountability in healthcare. An organisation’s conscience and capacity to progress is enhanced through governance strategies by exploring aspects of healthcare such as ‘how good and safe the service is’?, ‘how do I know this’? and ‘what can I do to make it (even) better’? The findings from this study demonstrate the medical records’ contents to be representative of consumers’ participation in their healthcare experience. The medical record is therefore a vehicle to facilitate governance and an opportunity to learn from experience. The following are
recommendations for improving the reliability and validity of the medical record as a data source:

 Depositing what the clinicians consider to be their responsibility for documenting clinical care, specifically decision making processes, will assist future research. Access to this information will allow researchers to include the local language and practices when customising their data collection tools; improving the relevance of the data for clinical practice. This information will also allow immediate actions to be taken in reference to professional and legal ramifications of any inadequate documentation practices.

 Depositing this study argues that higher level or recent completion of education, be it undergraduate, postgraduate or in-service programs has had minimal impact on documenting behaviours. In order to meaningfully understand when and what is likely to influence clinicians documenting practices a collaborative longitudinal study is recommended that compares the effectiveness of educational initiatives on clinicians views on documentation and record keeping behaviours.

 Depositing this study highlights the need for a review of how well and how we can improve the existing methods of appraising the professional conduct of employees, specifically the responsibilities and consequences for documentation, record keeping and safe practice that are enforced by individual healthcare organisations and relevant professional bodies.

 Depositing building on from this exploratory study’s findings and to meaningfully understand the significance of the consumer involvement in healthcare decision making data, it is recommended that further study be undertaken applying this study’s triangulated methods
Recommendations for Investigation Summary

The above areas for investigation represent the key themes that have emerged from this study. The scope of investigation ranges from the fundamentals of developing a common language that reflects the meaning of consumer participation in healthcare, to a collaborative debate about the relevance of a consumer oriented approach to healthcare decision making, and then to the deliberation about whether it is a priority of the consumer to be an equal partner in healthcare decision making. These recommendations are considered the building blocks for determining the roles and features of a healthcare philosophy that is consumer oriented. Until these attributes are determined, I consider that the medical records’ audit for indicators of consumer participation in decision making and information sharing, will provide the healthcare setting with a reliable indication of the existing level of participation activities. This audit data could then guide the facility in identifying and acknowledging its strengths and limitations, and assist in steering it towards achieving the positive health outcome measures associated with a healthcare model that empowers the individual.

Concluding Comments

In this chapter, the strengths and limitations of the study have been critiqued. Implications of the study, recommendations for addressing the significant findings and areas for further investigation have been presented. I believe that this study has contributed to the limited body of research related to capturing consumer involvement in decision making and information sharing. This study commenced with searching for indicators of joint responsibility, and has concluded with recommending strategies that facilitates shared understanding as a first step in building the organisations’, clinicians’ and consumers’ capacity to define the function of the consumer oriented model in contemporary Australian healthcare.

The study’s findings question the reliability of the aggregated consumer satisfaction data that is frequently used as a proxy measure of the success of existing consumer participation strategies. The findings strongly support
asking consumers about the expectations they hold for their healthcare experience and to revisit these expectations when measuring healthcare outcomes. In essence the findings question whether the drive for a consumer oriented approach to healthcare is representative of the views of the community, or instead the experts representing what they consider to be best for the community. The challenge is to continue to collaborate in defining the function of the consumer oriented model and to support a culture shift toward shared understanding as an antecedent of the healthcare relationship.

The medical records’ audit has been identified as the window into the consumer’s healthcare experience. The absence of evidence of consumer participation indicators in the record has been demonstrated to reliably represent evidence of absence of consumers participating in their healthcare decision making. The significance of having a shared understanding of the context or social reality of the consumer’s healthcare experience has been provided by the data from the Environmental, Clinician and Consumer Domains. Triangulating the study’s domains has permitted a valuable insight into the underlying hegemony that continues to dominate healthcare roles.

The study’s findings have taken me on a journey, well beyond my intended destination of simply determining the level of consumer participation activity in an Australian healthcare setting. In essence this study highlights that healthcare is a dynamic social relationship that brings together a diverse group of individuals; the interactions of these individuals and the environment that facilitates these interactions are influenced by, and have an influence on, the values, beliefs and behaviours of the wider community. This study and the questions that it raises for me, encourages me to pursue further research in this field.
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Reference List:


Appendix A

Clinician Survey
A survey for clinicians and clinical managers to self-assess their experiences in organising and managing clinical care
Dear Colleague,

We ask for about 45 minutes of your time to complete this questionnaire.

Our aim in this questionnaire is to obtain your views about a range of factors that affect your clinical work and how it is organised.

The results of the questionnaire will be used to develop a self-assessment tool that will enable clinicians, like yourself, to assess the organisation of care for patients and how this might be improved.

The study is funded by the Commonwealth Department of Health and Aged Care, the NSW Department of Health, the Queensland Department of Health and the Victorian Department of Human Services, in collaboration with the University of New South Wales. The statements in the questionnaire do not necessarily represent the views of any of these organisations.

We give an assurance that individuals responding to this questionnaire will not be identifiable in any reports of the findings. Hospital and University Ethics Committee approval has been obtained.

The questionnaire is divided into two parts. Part A includes basic demographic details and is designed to be a self-assessment tool about your current work practice. Part B explores your views on clinical practice and the environment in which you practice.

There are no right or wrong answers. We are simply interested in your views.

Thank you.
All questions in this survey relate to the organisation of care for patients undergoing a (please insert condition being investigated).

For the purpose of analysis we would like to know a few details regarding your position and location of work.

<table>
<thead>
<tr>
<th>Time</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ward</td>
<td></td>
</tr>
</tbody>
</table>

**Occupational/ Professional Background (Please tick as appropriate)**

**Nursing:**
- Nurse Clinician
- Theatre Nurse
- Midwife
- Nurse Manager

**Medical:**
- Physician
- Surgeon
- Anaesthetist
- Medical Manager

**Allied Health:**
Communicating the care process

1. By circling the appropriate response on the scale provided, indicate the extent to which you use the methods listed to determine 'what needs to be done next' for a patient undergoing the procedure.

   2. Always
   3. Frequently
   4. Sometimes
   5. Seldom
   6. Never

   I find out what needs to be done next for a patient undergoing the procedure through:
   - talking with the senior nurse/unit manager
   - meetings with other members of my occupational group
   - my occupational protocols/guidelines
   - information that is transmitted verbally in ward rounds or during a shift change over
   - referring to/knowing the 'doctors' individual preferences
   - the patient's medical record
   - therapy assessment form
   - talking with the patient
   - a hospital devised written clinical pathway

Patient involvement

1. Is there an information sheet given to patients undergoing the procedure, which outlines what they should expect as part of their routine clinical care?

   Yes ☐   No ☐

2. Do you use the information sheet in educating patients about their care?

   Always ☐   Frequently ☐   Sometimes ☐   Seldom ☐   Never ☐
5. For each of the dimensions of care listed below, indicate by ticking the appropriate box, whether your unit’s performance on caring for patients undergoing this procedure is benchmarked.

<table>
<thead>
<tr>
<th>The unit’s performance is benchmarked internally on......</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Resource usage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Composition of care</td>
<td></td>
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<tr>
<td>▪ Clinical quality</td>
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<td></td>
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<tr>
<td>▪ Patient feedback</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>The unit’s performance is benchmarked externally on......</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Resource usage</td>
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<tr>
<td>▪ Composition of care</td>
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<tr>
<td>▪ Clinical quality</td>
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<tr>
<td>▪ Patient feedback</td>
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</tbody>
</table>

Stability of clinical care settings

1. At this moment, how many other conditions are being treated in this ward?

Answer________________________ Don’t Know □
Part B

Improving the care process

Do you believe there are better ways of managing patients undergoing the procedure?

Yes   ☐   No    ☐

In point form, what changes would you like to introduce:

•
•
•
•
•
•
Basis for setting clinical care standards

By circling the appropriate response on the scale provided, indicate the extent to which the statements listed below correspond with your views about the basis for setting clinical standards.

1. A very appropriate consideration
2. An appropriate consideration
3. Neither an appropriate nor inappropriate consideration
4. An inappropriate consideration
5. A very inappropriate consideration

<table>
<thead>
<tr>
<th>Clinical standards should be based on:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>a clinician’s view of what works for her or him</td>
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<tr>
<td>locally accepted practice patterns within a hospital</td>
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<tr>
<td>documented and evaluated practice patterns across a number of hospitals</td>
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<tr>
<td>the latest developments in the medical, nursing and allied health literatures</td>
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<tr>
<td>protocols set by professional bodies and/or clinical colleges for medicine, allied health and nursing</td>
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<tr>
<td>what is acceptable to patients</td>
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<tr>
<td>what is feasible within existing resources</td>
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</table>
**Evidence Basis for Clinical Practice**

Rank the approaches listed below from 1 to 8 according to the extent to which they are used by you in determining patient treatment.

Place the numeral “1” next to the approach that you **most use**. Then place the numeral “2” next to the approach you **next most use** and so on, through to “8” for the approach that you **least use**.

**In ranking the approaches do not use the same rank more than once.**

<table>
<thead>
<tr>
<th>I base my clinical practice on the following:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Consensus within my clinical specialty</td>
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</tr>
<tr>
<td>Multidisciplinary pathway developed by my colleagues</td>
<td></td>
</tr>
<tr>
<td>Data derived from routine review of variances in our clinical management of patients</td>
<td></td>
</tr>
<tr>
<td>Literature review</td>
<td></td>
</tr>
<tr>
<td>Custom and precedent</td>
<td></td>
</tr>
<tr>
<td>Best practice guidelines by an external expert panel (eg Cochran Collaboration)</td>
<td></td>
</tr>
<tr>
<td>Clinical practice guidelines developed by professional colleges</td>
<td></td>
</tr>
<tr>
<td>Own clinical experience</td>
<td></td>
</tr>
</tbody>
</table>
From the statements listed below, select **ONE** which best describes your experience of managing clinical practice variations for patients undergoing the procedure.

[Please tick ONE only]

- I have never attended a meeting at which clinical practice variations have been discussed.

- I have attended some meetings at which practice variations have been discussed however the meetings were unproductive so I won't be going again.

- I am an active participant in meetings at which practice variations are discussed but find that their usefulness is limited because other people who are integral to the care process rarely or never attend.

- I, along with other members of the multidisciplinary team (including allied health, doctors and nurses) involved in managing patients undergoing the procedure, routinely attend meetings at which variations are discussed and, where appropriate, the care process is altered.
Accountability

By circling the appropriate response on the scale provided, indicate the extent to which you regard each of the arrangements listed below as being within your perception of your accountability.

1 Is Very important to my perception of my accountability
2 Is Important to my perception of my accountability
3 Is Slightly important to my perception of my accountability
4 Is Irrelevant to my perception of my accountability
5 Contradicts my perception of my accountability

An expectation that I:

- answer to myself for the way that I have acted in the interest of each of my patients

- participate with all staff in a multidisciplinary clinical team (involving doctors, nurses and allied health staff) in evaluating and improving the team’s collective performance

- answer to hospital management for the resource implications of my clinical practices

- answer to myself for the way that I have balanced the needs of individual patients with those of all other patients particularly with respect to resource usage

- review my clinical work with peers in my occupational group (within medicine, nursing, allied health) using evaluation criteria we have defined

- have my clinical work routinely reviewed by senior members of my occupational hierarchy (ie within medicine, nursing, allied health) using evaluation criteria defined by them

- be open to public scrutiny and provide justification for my clinical practices and resulting clinical outcomes

- answer to my patients for my clinical practices and resulting clinical outcomes.
By circling the appropriate response on the scale provided, indicate for each of the strategies listed below its order of priority.

1. A strategy of the **highest priority**
2. A strategy of **middle order priority**
3. A strategy of **low priority**
4. Not an **appropriate** strategy at all

To address resource issues that confront hospitals, health authorities should:

- Increase government funding to public hospitals
- Appoint clinicians to manage both the clinical and resource dimensions of hospital-based care
- Implement quality management methodologies
- Engender public debate about the resource limits that should be placed on the acute care component of the health care system
- Develop modes of service delivery which enable more patients to be treated without resort to hospital inpatient services
- Improve the ability of hospital information systems to monitor the work of clinicians
- Introduce casemix-based hospital funding
- Require medical colleges to develop and implement clinical pathways
- Engender public debate about the ethical limits of medical interventions.
## Attitudes to the organisation

We are interested in your general perceptions of this hospital.

By circling the appropriate response on the scale provided indicate for each of the statements listed below, the extent to which you 'agree' or 'disagree.'

1. Strongly agree
2. Agree
3. Undecided
4. Disagree
5. Strongly disagree

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>What the hospital stands for is important to me.</td>
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<tr>
<td>I &quot;talk up&quot; the hospital to my friends as a great organisation to work for.</td>
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<tr>
<td>If the values of this hospital were any different from what they are, I would not be as attached to this organisation.</td>
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<tr>
<td>How hard I work for the hospital is directly linked to how much I am rewarded.</td>
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<tr>
<td>In order for me to get rewarded around here, it is necessary to express the right attitude.</td>
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<tr>
<td>Since working at the hospital, my personal values and those of the hospital have become similar.</td>
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<tr>
<td>My private views about the hospital are different from those I express publicly.</td>
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<tr>
<td>The reason I prefer this hospital to others is because of what it stands for, that is, its values.</td>
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<tr>
<td>Unless I'm rewarded for it in some way, I see no reason to expend extra effort on behalf of the hospital.</td>
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<tr>
<td>I am proud to tell others that I am part of this hospital.</td>
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<tr>
<td>I feel a sense of &quot;ownership&quot; for this hospital rather than being just an employee.</td>
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<tr>
<td>Right now, staying with this hospital is a matter of necessity.</td>
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<tr>
<td>Too much in my life would be disrupted if I decided I wanted to leave this hospital now.</td>
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</tbody>
</table>
Highest Clinical Qualification

- Postgraduate Degree
- Degree
- Diploma
- Other (please specify)

--------------------

Highest Qualification in Management:

- Postgraduate Degree
- Postgraduate Diploma
- Undergraduate Degree
- Diploma
- Certificate
- Inhouse short courses
- None

*The Centre for Hospital Management & Information Systems Research
Thank you very much for taking the time and effort to complete this questionnaire*

*Feel free to use this space to comment on any issues raised in the survey*
Appendix B

Consumer Survey
C-section

Patients who have had a hospital experience of a survey of the recent
We thank you for your valuable assistance.

Please return the form in the free post envelope provided. No stamp is needed.

Your answers will be kept completely confidential.

For any comments you may wish to make, you are invited to fill in the spaces at the end of the survey, and the sheet is available at present.

There are no right or wrong answers. If you feel you need help deciding what sort of service you feel your hospital and the staff is offering, or if you feel there is an area of the survey that might need to be improved, please write a note on it. You can indicate your comments at the end of the survey.

The survey begins with some questions about you. This section helps us ensure that patients from different backgrounds receive similar quality healthcare. Completion of this section is desirable but not essential.

The survey is designed to assess what we need to do to improve health care for our patients.

Dear Patient,
1. Which age group are you?

- 35-44
- 25-34
- 18-24

2. Is this your first baby?

- Yes

3. Which of the following best describes your ethnic origin?

- Asian
- Aboriginal or Torres Strait Islander
- Chinese
- Middle Eastern
- Mediterranean
- Other (please specify) (please specify)

4. What is your postcode at home (ie the place where you usually live)?

Please use a black or blue pen to tick the appropriate box to answer the following questions.
7. What is your religion?

☐ Other (Please specify)

☐ No religion

☐ Muslim

☐ Jewish

☐ Hindu

☐ Christian

☐ Buddhist

6. What was the total income of your household last year (before tax)?

☐ $65,000+

☐ $35,000 to $65,000

☐ $20,000 to $35,000

☐ Less than $20,000

5. What was your highest educational attainment?

☐ Completed postgraduate qualification

☐ Completed undergraduate degree

☐ Completed technical college

☐ Completed high school

☐ Completed primary school
NURSING

9. The information provided on admission about the order of activities in relation to your care was...

8. The overall admission procedures upon entering the hospital were...

ADMISSION

This option indicates that the aspect being rated doesn’t apply to your situation.

6. Not Applicable
5. Don’t Know
4. Poor
3. Just Acceptable
2. Good
1. Excellent

(1) This option refers to exceptional service that could not be improved.

(2) This option indicates that you have no opinion.

SECTION 2: RATING YOUR HOSPITAL STAY

Using a black or blue pen and following the scale listed below, please circle the appropriate number to indicate how you would rate each of the following aspects of your hospital stay for:...
Facilities

For your baby was...

The information provided to you about the community services available to assist you in case...

In the 2 weeks after discharge was...

The information provided to you about whom you should contact if you need medical help...

The amount of time it took to complete the discharge process was...

In planning your discharge, the coordination given to your ability to manage your recovery at home was...

The amount of time you were given to prepare for home discharge home was...

Discharge

The way the hospital staff worked together to coordinate different aspects of your stay in hospital was...

The doctor and therapists' coordination with each other about your condition and care was...

The nurses and therapists' coordination with each other about your condition and care was...

The doctors and the nurses' coordination with each other about your condition and care was...

Coordination of Care

I. Strongly Agree
2. Moderately Agree
3. Lended
4. Moderately Disagree
5. Mostly Disagree
6. Not Applicable

Circle the number that best describes how much you agree with the statements below about your treatment.

1. The quality of the nurses during my stay in the hospital was... [Scale 1-5]
2. The provision of privacy for discussions with medical staff about your baby's condition and care was... [Scale 1-5]
3. The provision of privacy for discussions with medical staff about your condition and care was... [Scale 1-5]
**AFTER DISCHARGE**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>N</td>
<td>X</td>
</tr>
<tr>
<td>N</td>
<td>X</td>
</tr>
<tr>
<td>N</td>
<td>X</td>
</tr>
<tr>
<td>N</td>
<td>X</td>
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<tr>
<td>N</td>
<td>X</td>
</tr>
<tr>
<td>N</td>
<td>X</td>
</tr>
</tbody>
</table>

Since discharge, my baby has been readmitted to hospital for problems resulting from the birth.

Since discharge, my baby has been prescribed medications for problems resulting from the birth.

Since discharge, my baby has seen a doctor because of problems resulting from the birth (e.g., infection).

Since discharge, I have been readmitted to hospital for problems resulting from the cesarean section.

Since discharge, medications have been prescribed for me to treat the problems resulting from my cesarean section.

Since my discharge, I have seen a doctor because of problems resulting from my operation (e.g., infection, ongoing pain).

Since my discharge, I have seen a doctor in relation to my cesarean section for checkups only.

---

**EARLY DISCHARGE / EXTENDED MIDWIFE / PROGRAM OR HOSPITAL IN THE HOME**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>X</td>
</tr>
</tbody>
</table>

The nurse/doctor who attended me at home was courteous and calm.

The nurse/doctor who attended me at home came as often as was needed.

The nurse/doctor who attended me at home stayed as long as was needed.

The nurse/doctor who attended me at home explained things.

The reason for part of my care being at home were satisfactory explained to me.

---

Please circle X or NO to indicate whether you agree or not with the statements below about early discharge,
<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>60. Six months after birth my baby was not breastfed at all.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>61. Six months after birth my baby was breastfed and receiving complementary foods.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>62. Twelve weeks after birth my baby was breastfed and receiving complementary foods.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>63. Six weeks after birth my baby was fully breastfed.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>64. Six weeks after birth my baby was fully breastfed.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>65. At four days I left hospital my baby was fully breastfed.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>66. At four days I left hospital my baby was breastfed and receiving complementary foods.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>67. At four days I left hospital my baby was breastfed and receiving complementary foods.</td>
<td>N</td>
<td>A</td>
</tr>
<tr>
<td>68. At four days I left hospital my baby was breastfed and receiving complementary foods.</td>
<td>N</td>
<td>A</td>
</tr>
</tbody>
</table>

**Breastfeeding**

**Antenatal Care**


The statements below are about your treatment. (1) Strongly Agree 2. Moderately Agree 3. Undecided.
Appendix C

Medical Record
Participation Indicator Audit Tool
Medical Record Participation Indicator Audit Tool

**Evidence recorded within the hospital medical record of women’s involvement/inclusion in decision making about their care.**

Indicators –
- **Overt** – obvious documentation e.g. discussed with patient, explanation given by the caregiver to the woman & by requests made by either woman/caregiver
- **Indicative/implied** – e.g. suggested listening, evaluation of situation, wait & see (no active decision), expression of emotion, supportive actions
- **Absence**

<table>
<thead>
<tr>
<th>MRN</th>
<th>Context of care</th>
<th>Overt Indicators</th>
<th>Indicative/Implied Indicators</th>
<th>Absence of Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
Appendix D

Review of Caesarean Delivery w/o complicating diagnosis

MRN_____________   Financial category ___________              DOB__/__/____
Surname     First name    Address              Age_________  ________________________________________

Quality of care indicators
Admission Date                                                    Adverse Event:     Dependency on Arrival
Discharge Date                                                     Re-admission         Key: 1 Self caring 2 Min. Assist 3 Mod. Assist 4 Total
Operation Date                                                     Clinical Indicator: Apgar score 4 or below at five minutes
Length of Stay                                                                 6 or below at ten minutes
CMO 37/40 or > baby admitted/transfered to NICU

Maternal Obstetric History
Gravida_____Parity______Gestation_________Blood Group______
Antenatal Care - Midwives Clinic Shared Care Obstetrician
Antenatal Classes Referral Pre-Admission Clinic
Caesarean - Emergency Elective Primary Repeat -  Indicator
Anaesthetic- GA Epidural Spinal Other
Estimated Blood Loss _________mls

Post-op pain management

Baby Sex  Male  □ Female  □  Birth weight ________gms
Apgars 1min □ 5min □ 10min □ Discharge weight ______gms

Significant Medical/Social History

Consults

Allied Health
# Appendix D

## Quality of Care by Documented Evidence in Medical Record

*Rating Key 1. Complete 2. 1/3 documentation missing 3. 1/3 documentation present 4. No documentation*

<table>
<thead>
<tr>
<th>Category Rating</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Post-operative Care</td>
<td>MO Attendance</td>
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<tr>
<td>Observation</td>
<td></td>
<td></td>
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<td></td>
<td>IV Therapy</td>
<td>Admission</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Begin Discharge Plan</td>
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<td></td>
<td>Specific Analgesia OBS</td>
<td>Post-Operative</td>
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<tr>
<td>Pre-Operative Care</td>
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<td>Catheter care</td>
<td>Discharge</td>
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<tr>
<td>Consent Form</td>
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<td></td>
<td></td>
<td></td>
<td>Fluid Balance Chart</td>
<td>MO Legibility</td>
<td></td>
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<tr>
<td>Patient Prepared</td>
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<td></td>
<td>Diet</td>
<td>Notes</td>
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<td>ID Check</td>
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<td>Nursing Assessment Forms</td>
<td>Medication orders</td>
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<tr>
<td>Observation</td>
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<td>Post-operative</td>
<td>Discharge Planning</td>
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<td>Patient Involvement</td>
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<td>Theatre</td>
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<td>Follow-up GP</td>
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<td>Anaesthetic report</td>
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<td></td>
<td>Community Nurse</td>
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<td>RN’s report</td>
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<td>Other</td>
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<td>Recovery report</td>
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<td>Discharge Summary</td>
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### Adverse Events

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<th>Criteria</th>
<th>Date</th>
<th>Loc</th>
<th>Special</th>
<th>Attrib</th>
<th>Bed Day</th>
<th>Prevent</th>
<th>Criterion Notes</th>
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</tbody>
</table>

### Notes
Appendix E

Consumer Demographic Data
Appendix E.1 Site A Consumer Demographics

Eighteen completed consumer surveys were received and reviewed from a possible thirty consenting and contactable consumers, providing a response rate of 60%. Table E.1 displays the returned responses. The survey responses were assessed as to their representation of Site A’s sample of forty-one medical records. For example, the survey responses that stated this was their first baby (demographic variable) included 5 women (frequency of variable). The medical record sample indicated 9 women experienced their first birth. The consumer survey sample for this variable was representative of 5/9 or 55% of the medical record sample.

Table E.1 Consumer Demographics as representative of Site A’s record samples

<table>
<thead>
<tr>
<th>Consumer Demographic Variables</th>
<th>Frequency of survey response variables</th>
<th>% Survey response variables / medical record sample variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 – 24 years</td>
<td>1</td>
<td>1/5 20%</td>
</tr>
<tr>
<td>25-34 years</td>
<td>12</td>
<td>12/22 54%</td>
</tr>
<tr>
<td>35-44 years</td>
<td>5</td>
<td>5/14 36%</td>
</tr>
<tr>
<td>First baby (primiparous)</td>
<td>5</td>
<td>5/9 55%</td>
</tr>
<tr>
<td>Subsequent baby (multiparous)</td>
<td>13</td>
<td>13/32 41%</td>
</tr>
<tr>
<td>Financial - Private</td>
<td>3</td>
<td>3/12 25%</td>
</tr>
<tr>
<td>Public</td>
<td>15</td>
<td>15/29 52%</td>
</tr>
</tbody>
</table>

Table E.1 showed that the eighteen consumer respondents represented each of the variables identified in the medical record audit. Primiparous (55%), 25-34 years (54%) and public (52%) women were the most frequent respondents.
Appendix E.2 Site B Consumer Demographics

Seventeen completed consumer surveys were received and reviewed from a possible twenty-three consenting and contactable consumers, providing a response rate of 74%. Table E.2 displays the returned responses. The survey responses were assessed as to their representation of Site B’s sample of thirty-nine medical records. For example, the survey responses that stated this was their first baby (demographic variable) included four women (frequency of variable). The medical record sample indicated seven women experienced their first birth. The consumer survey sample for this variable was representative of 4/7 or 57% of the medical record sample.

Table E.2 Consumer Demographics as representative of Site B’s record samples

<table>
<thead>
<tr>
<th>Consumer Demographic Variables</th>
<th>Frequency of survey response variables</th>
<th>% survey response variables / medical record sample variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 – 24 years</td>
<td>4</td>
<td>4/7 57%</td>
</tr>
<tr>
<td>25-34 years</td>
<td>9</td>
<td>9/25 36%</td>
</tr>
<tr>
<td>35-44 years</td>
<td>4</td>
<td>4/7 57%</td>
</tr>
<tr>
<td>First baby (primiparous)</td>
<td>4</td>
<td>4/5 80%</td>
</tr>
<tr>
<td>Subsequent baby (multiparous)</td>
<td>13</td>
<td>13/34 38%</td>
</tr>
<tr>
<td>Financial - Private</td>
<td>0</td>
<td>0 0</td>
</tr>
<tr>
<td>Public</td>
<td>17</td>
<td>17/39 44%</td>
</tr>
</tbody>
</table>

Table E.2 showed that the seventeen consumer respondents represented each of the variables identified in the medical record audit. Primiparous (80%), 18-24 years & 35-44 years (57%) and public (44%) women were the most frequent respondents.
Appendix E.3 Site C Consumer Demographics

Twenty-one completed surveys were received and reviewed from a possible thirty-four consenting and contactable consumers, providing a response rate of 62%. Table E.3 displays the returned responses. The survey responses were assessed as to their representation of Site C’s sample of thirty-nine medical records. For example, the survey responses that stated this was their first baby (demographic variable) included seven women (frequency of variable). The medical record sample indicated twelve women experienced their first birth. The consumer survey sample for this variable was representative of 7/12 or 58% of the medical record sample.

Table E.3 Consumer demographics representative of Site C’s record samples

<table>
<thead>
<tr>
<th>Consumer Demographic Variables</th>
<th>Frequency of survey response variables</th>
<th>% survey response variables / medical record sample variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 – 24 years</td>
<td>4</td>
<td>4/6 67%</td>
</tr>
<tr>
<td>25-34 years</td>
<td>15</td>
<td>15/28 54%</td>
</tr>
<tr>
<td>35-44 years</td>
<td>2</td>
<td>2/5 40%</td>
</tr>
<tr>
<td>First baby (primiparous)</td>
<td>7</td>
<td>7/12 58%</td>
</tr>
<tr>
<td>Subsequent baby (multiparous)</td>
<td>14</td>
<td>14/27 52%</td>
</tr>
<tr>
<td>Financial - Private</td>
<td>0</td>
<td>0 0</td>
</tr>
<tr>
<td>Public</td>
<td>21</td>
<td>21/39 54%</td>
</tr>
</tbody>
</table>

Table E.3 showed that the twenty-one consumer respondents represented each of the variables identified in the medical record audit. Primiparous (58%), 18-24 years (67%) and public (54%) women were the most frequent respondents.
Appendix F

Documentation Completeness Audit
F.1 Site A Medical Record Documentation Completeness Audit

This component of the data collection included a detailed examination of Site A’s medical record sample, using validated screening measures, to verify if the records were a complete source of documentation. The audit has been described as a ‘patient centred quality improvement program’ designed to ‘flag’ quality and safety issues through a medical record review methodology (QaRNS Review Manual 2000). The audit tool was adapted by the researcher to focus on collecting data that indicated presence of documents or that the record was complete (i.e. no evidence of incomplete documents).

The researcher aimed to use this method to assist in understanding whether clinicians diligently complete recording other quality indicators of care and the absence of recording consumer participation indicators is an atypical behaviour and a limitation of the data collection method, or are clinicians as blasé about recording validated quality indicators as they are in recording the study’s consumer participation indicators.

In preparation for undertaking the audit, the researcher reviewed the record sample across the study sites, so as to identify the principal systems of documenting care. Two documentation methods stood out, firstly, the clinical pathway, with provision for acknowledging completion of standardised defined care processes with a signature notation, and secondly, the unstructured handwriting of the progress notes.

The absence of a signature(s) on the pathway or to complete assessment forms /notes/ reports were defined as incomplete documentation of care. Absent documentation were defined as; the absence of the evidence of notation of a clinically significant event (eg consent) or the absence of notation within the time frames for clinicians, as determined by the QaRNS criteria number 20 & 21. Legibility of the documentation, including the clinician(s) signature and designation, were also assessed. To demonstrate
An overview of the documentation and coding for each of the medical records has been included in Table F.1 (p. v) This table demonstrates consistency between the researcher and the independent coder in assessment of ‘presence’ and ‘completeness’ of the documents. For example there was uniformity in assessment of the absence of consent forms, incomplete clinical pathways, and inconsistent discharge planning documentation. This finding indicates a high degree of interrater reliability of the record data collected for Site A. The independent coder auditing four records that had been excluded from the study can account for some of the minor discrepancies in the audit table. Documentation through the continuum of care was found to be predominantly inconsistent and incomplete.

The audit for content and completeness of the medical record sample reflects the predominantly absence of evidence of indicators of consumer participation from the previous audit. This finding suggests that the consumer participation indicator audit tool was capable of representing the evidence of participation indicators. Additionally, the absence of evidence of participation indicators is not just a limitation of the data collection method.

Apart from the supporting the researcher’s consumer participation audit method, Table F.1 has clearly detailed deficiencies or absence of a number of documents that may adversely impact on the quality and safety of healthcare. Although these findings are not central to the study’s objectives, the researcher considered them to significant to ignore.

For example, the pre-operative checklist was notable in its absence in 39 of the 41 records. This is a risk assessment checklist that details information related to the consumer’s preparation for theatre (e.g. last time food or
drink taken, blood test results available) and confirms the correct consumer, procedure and preparation. The checklist was evident in two of the records and clearly communicated the consumer’s progress from the pre-operative clinician to the theatre clinician. The absence of the preformatted risk assessment document in the remaining record samples had obvious clinical and legal implications.

Another example includes the absence of the surgical consent form for all private patients (12/12). The consent form is essentially a document that when signed and witnessed by the patient and doctor, implies informed consent. Two out of twenty-nine public patients consent forms were also found to be either incorrect or absent. Both these incidences would be flagged as a significant event in the QaRNS review (QaRNS criterion number 3). In the interest of the clinicians and patient's safety this issue warranted further investigation.

The third example, the incomplete multidisciplinary clinical pathway document, effectively obstructed rather than mapped the individual's healthcare trajectory. The absence of signatures to identify completion of care tasks and outcomes by all disciplines, and the absence of individualising the design of care by documenting variations from the clinical pathway, reflected the participation indicator data, were clinicians neglected to indicate undertaking information sharing and decision involvement by signing the pathway. This finding implies the avoidance of clinicians identifying completion of care processes or the individualising of healthcare.

Irrespective of the interpretation placed on the documentation deficiencies in the record sample, the audit data leads one to question the completeness of care provided and furthermore the quality and safety of that care.
Table F.1. Site A Medical Record Audit – Content and Completeness

<table>
<thead>
<tr>
<th>Significant findings from data extracted</th>
<th>Researcher Audit</th>
<th>Independent Coder Audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records Reviewed</td>
<td>41</td>
<td>45</td>
</tr>
<tr>
<td>Legibility</td>
<td>Signature/Designation difficult to decipher</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Pre-admission</td>
<td>Multidisciplinary Pathway 34 incomplete 34 records without physical examination report</td>
<td>No medical officer entry 29 records 34 records without physical examination report</td>
</tr>
<tr>
<td>Theatre</td>
<td>39 records without pre-operative / theatre identification check No consent 12 private pts 1 consents did not reflect procedure performed 1 record no evidence of consent.</td>
<td>No consent 12 private pts 2 consents incorrect – consent for appendectomy after caesarian but not for caesarian; consent for evacuation of haematoma after Caesarian 1 record no indication of consent</td>
</tr>
<tr>
<td>Postoperative</td>
<td>Midwifery/ Allied Health pathway 37 incomplete Observation forms - incomplete Medicine – progress notes – complete Private patients - no medical documentation- verbal orders transcribed by midwives</td>
<td>Medical officer entry in progress notes every 24hrs/ change of condition. Nursing notations entered at least once on a day shift and once night shift</td>
</tr>
<tr>
<td>Discharge</td>
<td>Midwifery/ Allied Health Pathway / Referral to extended services 30 Incomplete Medicine – progress notes – inconsistent Computer Discharge summary</td>
<td>10 records no evidence of medical / nursing discharge planning Completion of discharge planning basic and often inconsistently documented</td>
</tr>
<tr>
<td>Designing and Evaluating Care</td>
<td>No evidence of consumer documentation. Variations in clinical care not identified on pathway, occurrences documented in progress notes. Special needs and outcomes not completed.</td>
<td>No variance sheet to accompany pathway</td>
</tr>
</tbody>
</table>
Summary – Site A Medical Record Audit Findings

As intended, the audit to determine the completeness of the record sample, has provided data to suggest that the samples’ documentation was incomplete, with evidence of absence of documents and signatures to indicate the completion of care. An independent coding consultant, indicating a high level of interrater reliability of the data, supported these findings.

The significance of the findings for the researcher is the comparisons that can be drawn between the deficiency and the participation indicator documentation audits. This was considered a strength, due to the documentation deficiency audit being a validated method, demonstrating interrater reliability and suggesting that clinicians do not routinely document quality indicators, such as consent or pre-operative checklists. These findings imply that the absence of consumer participation indicators in the previous audit, are not a limitation of the audits capacity to locate and classify indicators and is not an oversight by the clinician, but likely an indicator that consumer participation was not evident.
F.2 Site B Medical Record Completeness Audit

This component of the data collection included a detailed examination of Site B’s record sample, using validated screening measures, to verify if the records were a complete source of documentation. Site B’s findings are shown in Table F.2 (p. ix) and the methodology has been detailed in Site A and Chapter Three of this study.

Table F.2 has demonstrated consistency between the researcher and the independent coder in the difficulties they experienced identifying completion of midwifery care, the comprehensive medical documentation postoperatively and the generally incomplete discharge documentation. This finding indicated a high degree of interrater reliability of the record data collected for Site B. The independent coder auditing one record less may account for some of the minor discrepancies in the audit table.

The content audit for completeness of the record sample supports the organisations traditional orientation to clinical disciplines functioning independent of each other and the consumer, rather than the contemporary multidiscipline patient centred model of care. These findings will be briefly summarised.

Barriers to continuity were evidenced by clinical disciplines documenting in isolation of each other. The medical documentation in the progress notes was reported by the independent auditor to be comprehensive in relevance to medical care and inconsistent/basic in relevance to midwifery care. Interestingly, it was also noted that there was no evidence in the progress notes of medicine and midwifery communicating with each other. To the extent that the surgeon did not even sign the theatre nurses report / count sheet. These findings suggested that coordination of care between disciplines would not be ‘optimal’.
Site B’s maternal clinical pathway, was used in this setting as a midwifery care guide, and was found to be the greatest barrier in attempting to track midwifery care for the consumer sample. The absence of signatures to define completion of structured care tasks, the outcomes of care being predefined and no evidence of care design being individualising by documenting pathway variances, precluded the evidence of care being provided as basic, if at all. These findings suggested that coordination of care would be adversely influenced by the absence of midwifery documentation or that midwives did perceive themselves as contributing to the coordination of care in this setting.
## Table F.2 Site B Medical Record Audit – Content and Completeness

<table>
<thead>
<tr>
<th>Significant findings from data extracted</th>
<th>Researcher Audit</th>
<th>Independent Coder Audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records Reviewed</td>
<td>39</td>
<td>38</td>
</tr>
<tr>
<td>Legibility</td>
<td>Name printed</td>
<td>Acceptable</td>
</tr>
<tr>
<td></td>
<td>Staff number next to signature</td>
<td></td>
</tr>
<tr>
<td>Pre-admission</td>
<td>No pre-admission clinic</td>
<td>Medical officer entries in 32 records</td>
</tr>
<tr>
<td></td>
<td>Admission postnatal ward</td>
<td>10 records without physical examination report</td>
</tr>
<tr>
<td></td>
<td>Maternity Pathway (midwife) all 39 incomplete</td>
<td></td>
</tr>
<tr>
<td></td>
<td>33 records entered by medical officer on admission</td>
<td></td>
</tr>
<tr>
<td>Theatre</td>
<td>Pre-operative / theatre identification check complete</td>
<td>All consent forms present</td>
</tr>
<tr>
<td></td>
<td>All consent forms present.</td>
<td>16 records only had ‘caesarean section’ recorded and not the specific type</td>
</tr>
<tr>
<td></td>
<td>Surgeon report – no estimated blood loss / surgeon does not sign theatre report/count sheet</td>
<td></td>
</tr>
<tr>
<td>Preoperative</td>
<td>Maternity pathway (midwife) all 39 incomplete</td>
<td>11 records – no entries by midwives at least once a shift, very difficult to determine completion of midwifery care.</td>
</tr>
<tr>
<td></td>
<td>Observation forms - incomplete</td>
<td>2 records – no medical entry every 24hrs/ change of condition. Medical notes most comprehensive of settings</td>
</tr>
<tr>
<td></td>
<td>Medicine – progress notes-complete</td>
<td></td>
</tr>
<tr>
<td>Discharge</td>
<td>Maternity Pathway checklist (midwifery) all 39 incomplete</td>
<td>19 records no evidence of midwifery discharge planning</td>
</tr>
<tr>
<td></td>
<td>No discharge summary,</td>
<td>Discharge planning basic on pathway</td>
</tr>
<tr>
<td></td>
<td>Copy of Perinatal data sheet</td>
<td>15 records no evidence of medical completion of discharge</td>
</tr>
<tr>
<td></td>
<td>Medicine – progress notes-inconsistent</td>
<td></td>
</tr>
<tr>
<td>Designing and Evaluating Care</td>
<td>Provision for consumer to sign pathway prior to discharge – incomplete</td>
<td>Variance box on pathway – incomplete, Care not signed as complete on pathway, documented in progress notes, difficult to track patient</td>
</tr>
<tr>
<td></td>
<td>Perinatal data sheet – consent not obtained before forwarding to GP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Variations from care pathway not identified on pathway or progress notes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No provision for consumer designed outcomes or special needs</td>
<td></td>
</tr>
</tbody>
</table>

ix
Summary – Site B Medical Record Audit Findings

The medical record audits intended review of the completeness of the documentation has demonstrated a number of findings significant to the objectives of the study and has established a high level of interrater reliability of the data. Two of the key findings, were the incompleteness of the midwifery documents and that the clinical disciplines functioned independently.

The medical documentation was found to be overall comprehensive in the recording of medical care and/or change of patient’s status. Medical clinicians dominated the pre-admission documentation and the content of the record in general was found to be medically orientated. These findings reflected the presence and theme of medical documentation of ‘consumer participation’ in the previous indicator audit.

Minimal midwifery documentation, also a reflection of the participation indicator audit, was found to be disorganised, inconsistent and basic. In accordance with the medical dominance of the setting, the maternal clinical pathway was sanctioned by the medical clinicians and was designed to standardise midwifery care. The researcher assumes that the midwives choosing to ignore the pathway, was a ‘rebellion’ against this dominance. It also suggests that the midwives may be using an alternate form of communication, and that it is unlikely that the midwives would be capable of overtly impacting on the design of healthcare in this setting. In other words, although there is an absence of midwifery documentation, the researcher considers that it would be unlikely that the midwives would be able of influencing the consumer’s participation beyond the passive level in this setting.
F.3 Site C Medical Record Documentation Completeness Audit

An overview of the documentation and coding for each of Site C medical records has been included in Table F.3 (p. xiii).

Table F.3 demonstrated that both the researcher and independent coder had difficulties reviewing the records due to Site C’s haphazard filing system and the variety of options available for clinicians to record completion of clinical care. This resulted in the auditors either being unable to locate the clinician’s documentation or duplication of the clinician’s documentation on numerous forms. The researcher suggests that this may account for the minor audit discrepancies, such as the admission and operative notes.

It is also evident that the independent coder did not consider the incomplete clinical pathway throughout each episode of care as significant. It was obvious however to both auditors that there was minimal integration of clinical disciplines documentation, apart from the documents being filed in the same record. The discharge documentation was noted to be comprehensive, yet the range and variety of methods available to record discharge information obstructed the record review.

For these reasons the researcher considered that a degree of interrater reliability of the data collected, in relation to the presence and completeness of documents in the record sample for Site C, could be supported.

The audit for completeness of the record sample, has supported that each episode of care demonstrated a degree of documentation deficiency. It is noteworthy that the admission documentation is incomplete, this supports the participation indicator audit that identified the presence of indicators were likely to be recorded prior to admission. The organisation of the record documents supported that a traditional orientation to the organisation of clinical work, rather than the contemporary multidiscipline
model of care existed. The data suggests that the clinical disciplines documented in isolation of each other. This practice would adversely influence the continuity of care and the consumer’s ability to be included or participate in healthcare planning.

The researcher identified that the, ‘Clinical pathway post caesarean section’, was one of several pathways designed for the midwives only, indicators were organisationally defined as outcomes, and provisions were made for recording consumer’s special needs and clinical variances. However, the absence of midwives signatures to define completion of structured care tasks, and the absence of outcomes of care or evidence of care design being individualising by documenting pathway variances, precluded evidence or coordination of midwifery clinical care.
### Table F.3 Site C Medical Record Audit – Content and Completeness

<table>
<thead>
<tr>
<th>Significant findings from data extracted</th>
<th>Researcher Audit</th>
<th>Independent Coder Audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records Reviewed</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>Legibility</td>
<td>Employee Number after signature</td>
<td>Acceptable</td>
</tr>
</tbody>
</table>
| Pre-admission                            | No Pre-admission clinic  
Admission Postnatal ward  
Clinical Pathway – Midwife only sign  
– 30 incomplete  
Medical officer – progress notes | 23 records not entered by medical officer on admission |
| Theatre                                  | All consent forms present  
Surgeon report-computerized no signature (multiple copies) or handwritten (confusing) | All consent forms present  
26 records only had ’caesarean section’ recorded and not the specific procedure.  
19 records difficult to identify the medical operative notes |
| Post-operative                           | Clinical Pathway – midwife only sign  
23 incomplete  
Medical Officer / Allied Health entries in progress notes | 7 records no nursing notation at least once a day/night shift.  
3 medical officer entry notes incomplete |
| Discharge                                | Discharge Pathway –9 incomplete  
Progress notes -Discharge Stamp  
Date: Time:  
Obstetric Discharge Summary- carbon copy in all files  
Early Discharge Program Summary | Discharge Documentation clear |
| General Comments                         | Variances not always identified/ documented on pathway. Duplication of pathway actions in progress notes. Medical records filed in a very haphazard fashion | Medical record staff could not tell if patients have been seen in an outpatient clinic prior to admission. The order of the medical records was all over the place |
Summary – Site C Medical Record Audit Findings

The medical record audits intended review of the completeness of the documentation has demonstrated a number of deficiencies in the documentation of clinical care and also the duplication of clinician’s documentation. Combined with a haphazard filing system, reviewing these records was an arduous task for the auditors. Despite these barriers there was a degree of interrater reliability of the data evident between the two auditors.

The diversity in methods and mediums of documenting clinical care and the ways in which the trajectory of care was organised in Site C has impacted on the completeness of the medical record. For example, the unstructured pre-admission processes and the multi-formatted operative documents were more difficult to track and interpret than the discharge processes. However, irrelevant of the processes, the consumer’s participation in designing care, did not appear to be a prerequisite to the clinicians organization or recording of clinical care.
Appendix G

Triangulation of the Study Findings
G.1 Site A’s Data Triangulation

The sampling processes undertaken in Site A, provided access to forty-one (41) medical records with the code caesarean delivery without complicating diagnosis. Three hundred and eleven (311) clinicians were identified as documenting in this sample of medical records. A self selected stratified sample of thirty-two (32) clinicians, twenty-four (24) midwives/theatre nurse and eight medical officers participated in the survey. Eighteen (18) consumers from the sample of forty one medical records volunteered to participate in the study.

As intended, the demographic variables from each of the samples provided a broad background of the population, for Site A’s record samples. In summary, predominantly the medical record samples in this study were classified as being public (non-chargeable) financial category (71%), the maternal age reflected the population for childbearing women (25-34yrs). The women’s prior birth experiences ranged from their first birth to fourth birth, however they were more likely to have experienced childbirth before (78%) and that that experience was likely to have been a caesarean section (87%).

The stratified clinician samples represented the distribution of clinical disciplines in the clinical setting, with midwives (58%) outnumbering medical clinicians (24%). From the clinicians who responded, they were likely to have acquired tertiary education (81%) and be permanent staff, employed on a full or part time basis (93%).

The eighteen consumers that responded represented each of the demographic variables identified in the medical record audit. Primiparous (55%), 25-34 years (54%) and public (52%) women were the most frequent demographic variables.
The researcher considered these samples were a reasonable representation of a clinically homogeneous group, which adequately reflected the demographics of the elective caesarean section population in a public healthcare setting.

To facilitate triangulation of the environment, clinician, consumer and medical record domains, the key findings were tabled.

G.1 Site A’s Domain Summary

<table>
<thead>
<tr>
<th>Site A Mission Statement</th>
<th>‘To excel as an organisation which provides leadership in the provision of health services.’ stated belief that patients have the right to participate in the planning of their own health care, invited comments or suggestions about the ways in which services could be improved.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Environment 1.1 Walk Through</td>
<td>Bastian’s (1996) Organisational Participation Framework defined Site A’s consumer activity as ranging from the ‘Open Involvement’ to the ‘Restricted Scope’ level – where consumers were possibly consulted, however these were likely to be ‘token’ consultations with experts advocating their perceptions of consumers views.</td>
</tr>
<tr>
<td>1.2 Clinician Survey</td>
<td>(78%) of clinicians viewed it very appropriate or appropriate that clinical standards should be based on what was acceptable to patients (consumers) (40%) of clinicians agreed to some extent that consumers should be involved in setting clinical standards.</td>
</tr>
<tr>
<td>1.3A Organisational Characteristics</td>
<td>Discipline specific work structure Clinical work management medical based Input (cost) focused reporting mechanism</td>
</tr>
<tr>
<td>1.3B Management orientation</td>
<td>Quality/ adverse events reviewed (Corporate) Quality and Complaints reviewed (Clinical directorate) Multidisciplinary review (Clinical Unit)</td>
</tr>
</tbody>
</table>
Site A Environmental Domain Summary

The environmental domains walk through suggested that the consumer would be likely to form the view that the organisation was orientated towards collaborating and developing healthcare partnerships within a contemporary ‘active consumer orientated’ healthcare model. In this case consumers may have the expectation that clinicians would demonstrate behaviours such as consistency in information sharing, facilitating involvement in decision making and coordination of clinical care.

In detailing the organisational structure and processes of the setting’s orientation, the setting demonstrated propensity for standardisation, participation and a focus on quality. However, clinical work continued to be operationalised within the traditional medical model. The clinicians cynically described the organisations participation intentions to be tokenistic and then their self reported views towards involving consumer’s participation reflected identical attributes.

These findings suggested that the setting operated under the façade of a consumer orientated philosophy in that the organisation and the clinicians’ interpreted consumer’s needs and then designed the appropriate clinical care. This implied that information sharing and decision making approach by clinicians fell within Charles (1999) ‘informed choice’ and ‘paternalistic’ decision making spectrums. This meant the clinician controlled the direction of information flow, the information was diverse but it was medically based and it was likely that the provider alone decided treatment; however, some clinicians may have left the deliberation to the consumer. Consequently the consumer’s role in healthcare care design would be dependent on the clinicians approach, this approach may be different dependent on the clinician and therefore it would be likely that the consumer would adopt a ‘passive’ role due to these inconsistencies.
### 2. Clinician

#### 2.1 Organisation of Care

- **Form to sequence care for elective caesarean section patients**
  - Multidisciplinary – Medicine, midwifery, allied health
  - Care sequenced - One form
  - Outcome capacity - Organisational
  - Care Individualised – Variances/special needs
  - Quality - No evidence of recorded outcomes/variances used to review care, no obvious feedback mechanisms

- **Comment** - Absence of the operating theatres contribution to the trajectory

#### 2.1A Clinician Survey

<table>
<thead>
<tr>
<th>Organisation of Care data</th>
<th>Twenty eight (85%) clinicians knew of the form</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7/8 doctors <em>knew</em> of the form – none (0) <em>used</em> or <em>recorded</em> variances from the form</td>
</tr>
<tr>
<td></td>
<td>17/19 midwives <em>knew</em> – 16 <em>used</em> and 14 <em>recorded</em> variances</td>
</tr>
</tbody>
</table>

#### 2.2 Provision of Consumer Information

- Site A Information sheet replicated the processes defined in their Multidisciplinary Clinical Pathway, describing the clinical disciplines roles in the woman’s care

#### 2.2 A Clinician Survey

<table>
<thead>
<tr>
<th>Provision of Information data</th>
<th>Twenty-five (78%) clinicians <em>knew</em> of an information sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Twelve (48%) always/frequently <em>used</em> the information sheet</td>
</tr>
</tbody>
</table>

#### 2.3 Communicating Patient Care

- Determined the clinicians preferred methods to find out what needed to be done next for caesarean section patients

#### 2.3 A Clinician Survey

<table>
<thead>
<tr>
<th>Communicating Patient Care Data</th>
<th>Twenty-one (84%) clinicians accessed the medical record</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Eighteen talked to patients or accessed occupational protocols/guidelines</td>
</tr>
<tr>
<td></td>
<td>Doctors preferred to access the medical record</td>
</tr>
<tr>
<td></td>
<td>Midwives preferences were spread across every method, more likely to access the pathway</td>
</tr>
<tr>
<td></td>
<td>Theatre nurses preferred to access occupational protocols/guidelines</td>
</tr>
</tbody>
</table>
Site A Clinician Domain Summary

The clinician samples demographics generated the assumption that the organisation of clinical care may be collaborative and coordinated.

The survey findings verified generalised awareness of the existence of an organisationally designed and supported form, that sequenced clinical care (84%) and of another form that provided consumers information about elective caesarean section care (78%). However, awareness did not transcend into behaviours. Furthermore, the absence of a coordinated approach to care was implied by the lack of evidence to suggest that clinical disciplines communicated the completion of or variances in clinical care by a standardised or coordinated method.

These findings suggested that clinical care was operationalised in a traditional discipline specific model rather than the contemporary collaborative model. The clinicians reported behaviours did not support that the consumer would be able to predict their clinical care path, would be likely to receive consistent information or would have experienced consistent clinician behaviours. Consequently consumers would be likely to have adopted a ‘passive’ role in care design due to inconsistency in clinician’s information and documenting behaviours.

The findings implied that the medical record was incomplete; however, it was accessible or accessed by most of the clinicians, therefore a common link in the organisational maze of communicating clinical care.
### 3. Consumer

#### Methods of including or determining consumer outcomes

Evidence of distribution of a combined satisfaction and service improvement survey. Consumer Held Pregnancy health record, with provision for consumers to record. Record evaluation undertaken and working party reviewing findings. *Audit revealed evaluation methods to be unsystematised, focused on organisational issues, with limited feedback or clinical impact evidenced from consumer survey, clinicians preferred verbal consumer feedback and consumers did not record on pregnancy record.*

#### 3.1 Consumer survey clinician Behaviour data (Aggregated)

- From ninety opportunities to rate clinician’s information sharing, inclusion in decision making and coordination behaviours positively,
- Fifty-nine (66%) consumers rated behaviours Excellent/Good
- Eighteen (20%) rated behaviours ‘just acceptable’
- Eight (9%) rated clinicians behaviours poorly
- Five (5%) were unable to rate behaviours
- Co-ordination of care between doctors and nurse/midwives was the most poorly rated behaviour

#### 3.2 Consumer data compared with medical record (Individual)

Consumer ratings of clinician’s behaviours was not validated as the documented evidence of discussion by clinicians, did not consistently correlate with the consumer indicating a positive rating for the clinicians information sharing and decision making behaviours. The more definite (assertive, articulated, persistent) the consumer was about their care design the more evidence of discussion recorded in the medical record.

#### 3.3 Consumer Survey Involvement in decisions data (Aggregated)

- Ten (55%) women rated their involvement in pregnancy care decisions and their satisfaction with involvement as positive.
- The remaining eight consumers rated their involvement / satisfaction as less than optimal.
- Satisfaction with involvement was more likely viewed by multiparous, 25-34yrs women
<table>
<thead>
<tr>
<th>3.4</th>
<th>Consumer Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Satisfaction with Involvement in decisions data (Individual)</td>
</tr>
<tr>
<td></td>
<td>Some women were satisfied with not feeling fully involved with pregnancy care decisions and some felt fully involved however they were not fully satisfied with that involvement. Dissatisfaction with involvement in pregnancy care decisions did not correlate with documented evidence of any situations, technical or process that may have influenced the consumer's views.</td>
</tr>
</tbody>
</table>
The eighteen consumer respondents represented each of the variables identified in the settings medical record audit. The patterns that emerged from the consumer’s responses suggested that individual disciplines behaviours were viewed positively, whilst the poorest rating was given at the boundaries of care, where coordination was dependent on effective communication of care between the disciplines.

Aggregation of the involvement and satisfaction with pregnancy care decisions responses indicated that just over half of the consumer sample rated their experience as having been positive. In contrast the other half of the sample perceived their involvement could have been improved or that their expectations were not met. Consumer satisfaction with involvement was more likely to be considered by multiparous, 25-34yrs women, while dissatisfaction was spread across the sample demographics.

The consumer’s expectations of clinicians’ behaviours and satisfaction measures with the corresponding medical record were found to be inconclusive when seeking evidence of situations, process or technical, which may have influenced the consumer’s evaluation of their experience. Consumers demonstrating assertive attributes were more likely to have documentation of discussions recorded.

Despite the consumers demonstrating capacity to play an ‘active’ role in evaluating clinical care, the clinical setting continued to focus on complaints and technical adverse events as their outcomes measures.
### 4. Medical Record

#### 4.1 Indicators of Consumer Participation

- 41 medical records audited
- 123 opportunities to document consumer participation through the pre-operative, post-operative and discharge documents
- Implied or overt indicators evidenced in 60 of the records
- Absence of indicators evidenced in 63 of the records

**Pre-operative documents**
- 39 (95%) records had any indicators evident

**Post-operative documents**
- 11 (26%) records had any indicators evident

**Discharge documents**
- 10 (24%) records had any indicators evident

#### 4.2 Overt Indicators & Demographic Data

- Association existed between the evidence of overt participation indicators through the care trajectory and the greater number of previous birth experiences and/or being a public patient
- Private consumer’s absence of indicators was correlated to absence of pregnancy and pre-operative documents.

#### 4.3 Overt indicators and documentation style

- Pre-operative overt indicators were associated with obvious discussion, information sharing and participation within the subjective language style. Documentation was however, of a superficial quality, with inclusion in deciding infant feeding modes more likely than inclusion in designing clinical care.
- The post-operative and discharge documentation was predominantly directive and clinical within an objective language style.
- A pattern emerged between the presence of indicators of consumer participation in the record and the participative directions in the pre-operative section of the preformatted documents that were not present in the post-operative and discharge directive overtones.

#### 4.4 Documentation Deficiency and Legibility

- High degree of interrater reliability of the audit data demonstrated.
- Acceptable documentation legibility
- Significant documentation deficiency evident in the pre-operative checklist, consent forms, private doctor documentation, multidisciplinary clinical pathway
- Documentation predominantly inconsistent and incomplete.
Site A Medical Record Domain Summary

The audit findings identified that documentation of consumer participation within the 41 record samples was generally of a superficial quality and a passive intent. Out of the 123 potential opportunities throughout the continuum of care to document consumer participation, be it either implied or overt, only 60 of these opportunities were capitalised on, whilst conversely 63 opportunities were overlooked or not recorded.

The audit identified that consumer participation indicators were more likely in the pre-operative documentation (95%) rather than postoperative (27%) or discharge (24%) documentation. The audit finding also suggested that overt participation indicators were associated with the consumer demographic variables; greater number of previous birth experiences and/or being a public patient and with issues that were unlikely to impact on the clinical organisation of care, such as infant feeding.

The validated documentation deficiency audit methodology acknowledged that the medical record samples were an incomplete documentation of the clinical encounter, with a number of quality and safety issues being revealed.

The audit has identified that were limitations to the completeness of the medical record. In particular, setting A’s record samples that were admitted under the ‘private financial category’ were found to be incomplete in the presence and the completion of documents, limiting the audit methodology as being representative of their generic healthcare experience let alone evidence of their participation.
G.2 Site B’s Data Triangulation

The sampling processes undertaken in Site B, provided access to thirty nine (39) medical records with the code caesarean delivery without complicating diagnosis. One hundred and seventy eight (178) clinicians were identified as documenting in this sample of medical records. A self selected stratified sample of thirty-four (34) clinicians, twenty five (25) midwives/theatre nurse and nine medical officers participated in the survey. Seventeen (17) consumers from the sample of thirty nine medical records volunteered to participate in the study.

As intended, the demographic variables from each of the samples provided a broad background of the population, for Site B’s record samples. In summary, the medical record samples in this study were classified as being public (non-chargeable) financial category (100%), the maternal age reflected the population for childbearing women (25-34yrs). The women’s prior birth experiences ranged from their first to their sixth birth, however they were more likely to have experienced childbirth before (87%) and that experience was likely to have been a caesarean section (82%).

The stratified clinician samples represented the distribution of clinical disciplines in the clinical setting, with midwives (53%) outnumbering medical clinicians (26%). The clinicians were likely to have acquired tertiary education (87%) and be permanent staff, employed on a full or part time basis (97%).

The seventeen consumers that responded represented each of the demographic variables identified in the medical record audit. Primiparous (80%), 18-24 years & 35-44 years (57%) and public (44%) women were the most frequent demographic variables.
The researcher considered these samples were a reasonable representation of a clinically homogeneous group, which adequately reflected the demographics of the elective caesarean section population in a public healthcare setting.

To facilitate triangulation of the environment, clinician, consumer and medical record domains, the key findings were tabled.

**G.2 Site B Domain Summary**

<table>
<thead>
<tr>
<th>Site B Mission Statement</th>
<th>‘Offering convenience and choice for you and your family’ The consultant obstetrician will discuss the options of antenatal care available to you on your initial visit.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Environment</td>
<td>Bastian’s (1996) Organisational Participation Framework defined setting B’s consumer activity as falling within the ‘Manipulation’ level, where the consumer was ‘educated’ or used as a source or recipient of information.</td>
</tr>
<tr>
<td>1.2 Clinician Survey</td>
<td>(82%) of clinicians viewed it very appropriate or appropriate that clinical standards should be based on what was acceptable to patients (consumers) (52%) of clinicians agreed to some extent that consumers should be involved in setting clinical standards.</td>
</tr>
<tr>
<td>1.3A Organisational Characteristics</td>
<td>Discipline specific work structure Clinical work management medical based Input (cost) focused reporting mechanism</td>
</tr>
<tr>
<td>1.3B Management orientation</td>
<td>Quality/adverse events reviewed by corporate management No clinical directorate or unit review of quality No multidisciplinary review</td>
</tr>
</tbody>
</table>
Site B Environmental Domain Summary
The environmental domains walk through suggested that the consumer would be unlikely to form the view that the organisation was orientated towards collaborating and developing healthcare partnerships. The organisational strategies, from the mission statement down, were predominantly not intended to seek participatory and feedback from consumers. The organisations intentions appeared to be paternalistic and sought to ‘educate’ or use the consumer as a source or recipient of information. Indifference and lack of concern were themes that arose from clinicians and line manager’s views of the organisations intentions to actively engage consumers. This confirmed that Site B viewed a ‘passive’ rather then an ‘active’ orientation of their consumers.

The organisational structure and processes of the site’s orientation suggested that Site B operated along the traditional medical model of clinical work, with no evidence of multidiscipline integration of care and reporting mechanisms predominantly budget focused.

The clinician’s views towards consumer’s participation were one of the most significant findings of this setting. The aggregated clinician responses were found to view consumer participation as an integral component in setting clinical care standards and accordingly reflected a shared decision making approach. This view did not replicate the environments orientation and suggested that the organisation was an obstacle to clinicians operating within a consumer- orientated model.

However, viewing the responses as independent disciplines, in accordance with the lack of discipline integration and the obvious medical dominance in the settings orientation and document design. The findings revealed that the doctors viewed that basing clinical care on what was acceptable to patients yet not involving them in designing the care was appropriate practice. This contradiction was a more accurate reflection of the settings suggested ‘paternalistic’ or ‘passive’ orientation to educating or manipulating consumers.
2. Clinician
2.1 Organisation of Care

<table>
<thead>
<tr>
<th>Form to sequence care for elective caesarean section patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single Discipline – Midwifery</td>
</tr>
<tr>
<td>Care sequenced – One form</td>
</tr>
<tr>
<td>Outcome capacity - Organisational Care Individualised – Variances</td>
</tr>
<tr>
<td>Quality – No evidence using pathway to review care</td>
</tr>
<tr>
<td>Comment - Medical orders were to be taken into account when following this pathway. Absence of the operating theatres contribution to the trajectory.</td>
</tr>
</tbody>
</table>

2.1A Clinician Survey Organisation of Care data

<table>
<thead>
<tr>
<th>Twenty two (65%) clinicians knew of the form</th>
</tr>
</thead>
<tbody>
<tr>
<td>3/9 doctors knew of the form – one (1) used and none recorded variances from the form</td>
</tr>
<tr>
<td>14/18 midwives knew – 12 used and 9 recorded variances</td>
</tr>
</tbody>
</table>

2.2 Provision of Consumer Information

| Site B did not have a condition specific information sheet endorsed by the organisation. Information providing was deemed primarily the responsibility of medical clinicians |

2.2 A Clinician Survey Provision of Information data

<table>
<thead>
<tr>
<th>Ten (29%) clinicians knew of an information sheet, five of the clinicians were doctors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Six out of ten (60%) always/frequently used the information sheet</td>
</tr>
</tbody>
</table>

2.3 Communicating Patient Care

| Determined the clinicians preferred methods to find out what needed to be done next for caesarean section patients |

2.3 A Clinician Survey Communicating Patient Care Data

<table>
<thead>
<tr>
<th>Twenty-eight (82%) clinicians accessed the medical record</th>
</tr>
</thead>
<tbody>
<tr>
<td>Twenty-seven (79%) preferred verbal ward rounds and twenty-four (73%) knew individual doctors preferences. Doctors preferred to access the medical record or ward rounds</td>
</tr>
<tr>
<td>Midwives preferences were spread across every method, more likely to access the record, ward rounds or pathway Theatre nurses knew individual doctors preferences or preferred to talk to the patient.</td>
</tr>
</tbody>
</table>
Site B Clinician Domain Summary

The clinician samples demographics generated the assumption that the organisation of clinical care may be collaborative and coordinated. However, the review of documents designed to organise and review clinical care suggested that care design would be medically dominated, with no evidence of integration. Precursors of poor quality and safety in healthcare were evident in the barriers to communication and coordination of clinical care.

The clinician samples self reported behaviours reiterated the organisation’s medical model of healthcare, with discipline specific behaviours that deferred to medical dominance. The regulation of midwifery care under the guidance of medical orders and the deference of information provision responsibility to medical clinicians supported the environmental domains findings of power imbalances. There was no continuity between disciplines in the processes of communicating the completion or variations in clinical care and in informing consumers of their projected clinical care path. These factors have been reputed to marginalise the consumer’s capacity to participate in designing their elective caesarean section care.

Of interest to this study, the clinician’s stated preference for the medical record, as the principle method of determining what needed to be done next for consumers, was a surprising finding. The method did not correspond with the diversity of the clinician samples reported communicating behaviours and their suggested allegiance with traditional discursive or just ‘knowing’ communication styles. The reported behaviours however did suggest that the clinical environment would be disruptive, susceptible to clinical errors and obstruct the consumer from actively participating in clinical care design.
### 3. Consumer

Methods of including or determining consumer outcomes

Evidence of the existence of a basic patient satisfaction survey. This setting used the traditional hospital held antenatal record, with a co-operation card that was held by the consumer.

*Audit revealed no accountability to distributing, collecting or analysing surveys. No evidence of feedback or clinical impact from consumer surveys. The antenatal record was designed for medical decision making, no inference to consumers evaluating or participating in care design.

#### 3.1 Consumer survey clinician Behaviour data (Aggregated)

From eighty five opportunities to rate clinician’s information sharing, inclusion in decision making and coordination behaviours positively:
- Sixty-seven (79%) consumers rated behaviours Excellent / Good
- Twelve (14%) rated behaviours ‘just acceptable’
- Three (4%) rated clinicians behaviours poorly
- Three (4%) were unable to rate behaviours

Doctor’s decision making behaviours (65%) were the least favourable rated behaviour, followed by the coordination of care (71%) between doctors and nurse/midwives.

#### 3.2 Consumer data compared with medical record (Individual)

Consumer’s ratings of clinician’s behaviours was not validated.

Medical documenting was fragmented, objective, medico-legal transcription of discussions; they referred to their medical hierarchy and used a standardised method of documenting medical decisions. There was minimal documented evidence of midwives behaviours. Therefore the presence of comprehensive documentation did not correlate to the consumer rating the clinician’s behaviours positively.

#### 3.3 Consumer Survey Involvement in decisions data (Aggregated)

Eleven (65%) women rated their involvement in pregnancy care decisions positive and ten women (59%) were satisfied with their involvement. Consumers did not give a negative rating.

Satisfaction with involvement was more likely viewed by multiparous, 25-34yrs women
3.4 Consumer Survey
Satisfaction with Involvement in decisions data (Individual)

The individual women’s assessment of involvement and satisfaction were unremarkable except for one consumer who considered herself fully involved in pregnancy care decisions yet only moderately satisfied with this involvement. The responses within the medical record content were also unremarkable due to the limited and objective documentation styles.

Consumer Domain Summary

The eighteen consumer respondents represented each of the variables identified in the settings medical record audit. The patterns that emerged from the consumer’s responses suggested that the medical decision making behaviours experienced were the least favourable, followed by coordination of care between clinical disciplines.

Aggregation of the involvement and satisfaction with pregnancy care decisions responses indicated that nearly two thirds of the sample perceived their inclusion in decisions, was positive. No-one gave an undecided/negative rating, allowing for the suggestion that there was potential for the women in this setting to have their expectations of involvement partially met.

The consumer’s expectations of clinician’s behaviours and satisfaction measures with the corresponding medical record were found to be inconclusive. The medical record content was limited by minimal evidence of midwifery behaviours and medical notations being predominantly objective and devoid of any participative terms.

The consumers views that their expectations of involvement were predominantly met, does not quantify the level of involvement being active or passive. It does however suggest that the consumers had formed an expectation of the level of involvement available. Interestingly the consumers giving doctors inclusion of consumers in decision making the poorest rating, suggests that the consumers were aware that their involvement in decisions was not optimal but what could be expected of the site.
### 4. Medical Record

#### 4.1 Indicators of Consumer Participation

- **39 medical records audited**
- **117 opportunities to document consumer participation through the pre-operative, post-operative and discharge documents**
- **Implied or overt indicators evidenced in 38 of the records**
- **Absence of indicators evidenced in 79 of the records**

**Pre-operative documents** - 34 (90%) records had any indicators evident

**Post-operative documents** - No (0) records had any indicators evident

**Discharge documents** – 3 (7%) records had any indicators evident

#### 4.2 Overt Indicators & Demographic Data

Association existed between the evidence of overt participation indicators through the care trajectory and the greater number of previous birth experiences, 35-44yrs and/or being a public patient.

Across all variables, as the consumer preceded through the healthcare trajectory a significant and consistent reduction in evidence of overt indicators occurred.

#### 4.3 Overt indicators and documentation style

- **Pre-operative overt indicators** were associated with medical documentation describing discussion, options and decision for proceeding with elective surgery.
- In contrast, medical documentation was dominated by medical clinician.
- Midwifery documentation was nominal.
- This was impacted by the service structure limiting the consumer’s exposure primarily to medical clinician.

The presence of overt indicators symbolised a paternalistic motivation rather than a participative process. The prevalence of indicators implied to the researcher a covert fear of litigation, rather than an overt inclusion of the consumer in designing care.

#### 4.4 Documentation Deficiency and Legibility

- **High degree of interrater reliability of the audit data demonstrated**.
- **Acceptable documentation legibility**
- **Significant documentation deficiency evident in the pre-operative admission and discharge processes of the clinical pathway, with all records incomplete**.
- Medical documentation comprehensive and dominated the record.
- Midwives documentation disorganised, inconsistent and basic.
Site B Medical Record Domain Summary

The audit findings identified that documentation of consumer participation within the 39 record samples were generally for medico/legal purposes and of a passive intent. Out of the 117 potential opportunities throughout the continuum of care to document consumer participation, be it either implied or overt, only 38 of these opportunities were capitalised on, whilst conversely 79 opportunities were overlooked or not recorded.

The audit identified that consumer participation indicators were more likely in the pre-operative documentation (90%) rather than postoperative (0%) or discharge (8%) documentation. The facade of a consumer centred orientation in the pre-operative period was revealed to simply reflect the settings paternalistic approach within the medical decision making model.

The validated documentation deficiency audit acknowledged that the record samples were an incomplete recount of midwifery/nursing clinical care, with a number of quality and safety issues present.

On reviewing the records the medical clinicians were the primary decision makers, consumer's agreement were sought and recorded. These findings represented consumers, and all those allied to medicine, in a passive role.
G.3 Site C’s Data Triangulation

The sampling processes undertaken in Site C, provided access to thirty-nine (39) medical records with the code caesarean delivery without complicating diagnosis. One hundred and ninety-two (192) clinicians were identified as documenting in this sample of medical records. A self selected stratified sample of thirty-eight (38) clinicians, twenty-seven (27) midwives/theatre nurse and eleven medical officers participated in the survey. Twenty-one (21) consumers from the sample of thirty-nine medical records volunteered to participate in the study.

As intended, the demographic variables from each of the samples provided a broad background of the population, for Site C’s record samples. In summary, predominantly the medical record samples in this study were classified as being public (non-chargeable) financial category (100%), the maternal age reflected the population for childbearing women (25-34yrs). The women’s prior birth experiences ranged from their first birth to third birth, however they were more likely to have experienced childbirth before (69%) and that that experience was likely to have been a caesarean section (78%).

The stratified clinician samples represented the distribution of clinical disciplines in the clinical setting, with midwives (50%) outnumbering medical clinicians (26%). From the clinicians who responded, they were likely to have acquired tertiary education (93%) and be permanent staff, employed on a full or part time basis (94%).

The twenty one consumers that responded represented each of the demographic variables identified in the medical record audit. Primiparous (58%), 18-24 years (67%) and public (54%) women were the most frequent demographic variables.
The researcher considered these samples were a reasonable representation of a clinically homogeneous group, which adequately reflected the demographics of the elective caesarean section population in a public healthcare setting.

To facilitate triangulation of the environment, clinician, consumer and medical record domains, the key findings were tabled.

**G.3 Site C Domain Summary**

<table>
<thead>
<tr>
<th><strong>Site C Mission Statement</strong></th>
<th>‘Helping people to better health and well-being’; achieved by encouraging individual responsibility for health care. Values – A commitment to quality outcomes through proper evaluation of all services; achieved by focusing on health care and consumer needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Environment</strong></td>
<td><strong>1.1 Walk Through</strong> Bastian’s (1996) Organisational Participation Framework defined setting C’s consumer activity as ranging from the ‘Restricted Scope’ to the ‘Manipulation’ level – where experts advocated their perceptions of consumer’s views or consumers being ‘educated’ in the ways of the organisation.</td>
</tr>
<tr>
<td></td>
<td>(89%) of clinicians viewed it very appropriate or appropriate that clinical standards should be based on what was acceptable to patients (consumers) (36%) of clinicians agreed to some extent that consumers should be involved in setting clinical standards.</td>
</tr>
<tr>
<td></td>
<td><strong>1.3A Organisational Characteristics</strong> Discipline specific work structure Clinical work management medical based Input (cost) focused reporting mechanism</td>
</tr>
<tr>
<td></td>
<td><strong>1.3B Management orientation</strong> No evidence of Quality/ adverse events reviewed (Corporate) Complaints only reviewed (Clinical directorate) Multidisciplinary review (Clinical Unit)</td>
</tr>
</tbody>
</table>
Site C Environmental Domain Summary

The environmental domains walk through suggested that the consumer would be likely to form the view that the organisation was orientated towards ‘sharing the responsibility’ of healthcare within the contemporary ‘active consumer orientated’ partnership model. In this case consumers may have the expectation that clinicians would demonstrate behaviours such as consistency in information sharing, enabling involvement in decision making and coordination of clinical care.

True to their mission statement, the organization had evidence of integrating evaluation methods into service provision. However the passive feedback mechanisms were designed to enable consumers to be active participants or in working partnerships with clinicians or the organisation. The data suggested that the organisation focussed on complaints. The organisation focus on ‘educating’ or using the consumer as a source or recipient of information supported the propensity for a ‘passive’ rather then an ‘active’ orientation for their consumers.

The clinician’s self reported views were also found to advocate that clinicians were responsible for interpreting consumer’s needs and then designing the appropriate clinical care. These views suggested that the traditional paternalistic decision making model was preferred over the consumer orientated model. Meaning that the clinician controlled the direction of information flow, the information may be diverse but medically based and it was likely that the provider would decide treatment. Consequently the consumer’s role in healthcare care design would be dependent on the clinicians approach, this approach may be different dependent on the clinician and therefore it would be likely that the consumer would adopt a ‘passive’ role due to these inconsistencies.
### 2. Clinician

#### 2.1 Organisation of Care

<table>
<thead>
<tr>
<th>Form to sequence care for elective caesarean section patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single Discipline – Midwifery</td>
</tr>
<tr>
<td>Care sequenced – Multiple forms</td>
</tr>
<tr>
<td>Outcome capacity - Organisational</td>
</tr>
<tr>
<td>Care Individualised – Variances / special needs</td>
</tr>
<tr>
<td>Quality – No evidence of recorded outcomes/variances used to review care, no obvious feedback mechanisms</td>
</tr>
</tbody>
</table>

**Comment** – Pre-Theatre, Post Caesarean Delivery, Neonatal Pathways, operating theatres contribution to the trajectory absent

#### 2.1A Clinician Survey Organisation of Care data

<table>
<thead>
<tr>
<th>Twenty four (63%) clinicians knew of the form</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/11 doctors knew of the form – none (0) used or recorded variances from the form</td>
</tr>
<tr>
<td>16/19 midwives knew – 14 used and 13 recorded variances</td>
</tr>
</tbody>
</table>

#### 2.2 Provision of Consumer Information

| Site C produced a generic information booklet and a caesarean section information booklet, medical clinicians also accessed discipline specific pamphlets |

#### 2.2A Clinician Survey Provision of Information data

<table>
<thead>
<tr>
<th>Twenty-five (66%) clinicians knew of an information sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>20/25 or 80% always/frequently used the information sheet</td>
</tr>
</tbody>
</table>

#### 2.3 Communicating Patient Care

| Determined the clinicians preferred methods to find out what needed to be done next for caesarean section patients |

#### 2.3A Clinician Survey Communicating Patient Care Data

<table>
<thead>
<tr>
<th>Twenty-two (71%) clinicians preferred to talk to their patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Twenty one (68%) accessed the medical record and twenty (64%) preferred ward rounds/verbal methods</td>
</tr>
<tr>
<td>Doctors preferred to talk to patients</td>
</tr>
<tr>
<td>Midwives preferences were spread across every method, more likely to access the pathway</td>
</tr>
<tr>
<td>Theatre nurses ‘knew’ individual doctors preferences.</td>
</tr>
</tbody>
</table>
Site C Clinician Domain Summary

The clinician samples demographics generated the assumption that the organisation of clinical care may be collaborative and coordinated.

However, the clinician samples self reported behaviours and practices have found these assumptions to be debatable. For example, there was some evidence of uniformity in the clinician’s awareness of a document that provided consumers with information about elective caesarean section care (66%) and even less consistency in awareness of a document that sequenced clinical care (63%). The findings identified that there was minimal continuity between disciplines in the processes of communicating the completion or variations in clinical care and in informing consumers of their projected clinical care path.

The range of organisational documents and their design were thought to be a contributing factor towards the clinician’s reported communication methods. It was suggested that the multiplicity of documents designed to sequence clinical care, the diverse sources of information and inconsistent documenting behaviours were barriers to effective communication alone. It was suggested that clinicians either viewed these issues as a barrier or clinicians viewed the approach as ‘sharing responsibility’. Either way the clinicians thought the consumer was the one who would most likely ‘know’ what was next. The findings did suggest that the medical record was accessible or accessed by clinicians; however it appeared that the clinicians ‘knew’ that the contents would not be capable of assisting them in tracking the clinical care trajectory. As a result, it is likely that the consumer functioned as a mediator for clinical disciplines rather than an active participant in designing care.

These findings identified a number of contradictions. The clinicians reported behaviours did not support that the consumer would be able to predict their clinical care path, would be likely to have received consistent information or have experienced consistent clinician behaviours. The consumer therefore, would be likely to have adopted a ‘passive’ role in care design.
### 3. Consumer

**Methods of including or determining consumer outcomes**

Reportedly in transition from a localised service evaluation to an organisational wide approach co-ordinated by a private consultancy. Suggestion forms were distributed high profile/ volume locations. Traditional hospital held antenatal record, with a co-operation card that was held by the consumer used.

*Audit revealed difficulties accessing previous evaluations, methods were unsystematised, limited feedback or clinical impact evidenced from survey. Organisation focused on complaints.*

<table>
<thead>
<tr>
<th>3.1 Consumer survey clinician Behaviour data (Aggregated)</th>
</tr>
</thead>
<tbody>
<tr>
<td>From one hundred and five opportunities to rate clinician’s information sharing, inclusion in decision making and coordination behaviours positively: Eighty-eight (88%) consumers rated behaviours Excellent/Good Twelve (11%) rated behaviours ‘just acceptable’ Two (2%) rated clinicians behaviours poorly Two (2%) were unable to rate behaviours Co-ordination of care between doctors and nurse/midwives was the most poorly rated behaviour</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.2 Consumer data compared with medical record (Individual)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers ratings of clinician’s behaviours was not validated as the documented evidence of discussion by clinicians, did not consistently correlate with the consumer indicating a positive rating for the clinicians information sharing and decision making behaviours. For example minimal evidence of nurse/midwives behaviours in the record, were consistently rated positively, in contrast doctors comprehensive documentation, was rated poorly or just acceptable by the consumers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.3 Consumer Survey Involvement in decisions data (Aggregated)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thirteen (65%) women rated their involvement in pregnancy care decisions and their satisfaction with involvement as positive. The remaining consumers rated their involvement / satisfaction as less than optimal, undecided or negative experiences. Satisfaction with involvement was more likely viewed by multiparous, 25-34yrs women</td>
</tr>
<tr>
<td>3.4 Consumer Survey</td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td>Satisfaction with Involvement in decisions data (Individual)</td>
</tr>
</tbody>
</table>
Site C Consumer Domain Summary

The twenty one consumer respondents represented each of the variables identified in the settings medical record audit. The patterns that emerged from the consumer’s responses suggested that individual disciplines behaviours were viewed positively, whilst the poorest rating was given at the boundaries of care, where coordination was dependent on effective communication of care between the disciplines.

Aggregation of the involvement and satisfaction with pregnancy care decisions responses indicated that nearly two thirds of the consumers rated their experience as a positive outcome measure. The remaining consumers rated their involvement / satisfaction as less than optimal, with one consumer strongly disagreeing with being fully involved in pregnancy care. Consumer satisfaction with involvement was more likely to be considered by multiparous, 25-34yrs women, while dissatisfaction was spread across the sample demographics.

The consumer’s expectations of clinician’s behaviours and satisfaction measures with the corresponding medical record were generally found to be inconclusive and limited by the medicolegal documentation style of medical clinicians. A number of contradictions were identified, for example a consumer reported lack of involvement in decisions was supported by documentation suggesting that the woman’s experiences were less than optimal, however the consumer then expressed satisfaction as her outcome measure.

The researcher suggested that the inconsistencies of consumer’s perceptions of inclusion and their satisfaction measures could be seen as a reason why the organisation focussed on complaints and technical adverse events as their principal outcome measures. Detailing the consumers experience could be seen as confronting and challenging to the organisation and the clinician.
4. Medical Record

4.1 Indicators of Consumer Participation

<table>
<thead>
<tr>
<th>Description</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical records audited</td>
<td>39 medical records</td>
</tr>
<tr>
<td>Opportunities to document consumer participation</td>
<td>117 opportunities</td>
</tr>
<tr>
<td>Implied or overt indicators</td>
<td>Implied or overt indicators evidenced in 53 of the records</td>
</tr>
<tr>
<td>Absence of indicators</td>
<td>Absence of indicators evidenced in 64 of the records</td>
</tr>
<tr>
<td>Pre-operative documents</td>
<td>Pre-operative documents- 39 (100%) records had any indicators evident</td>
</tr>
<tr>
<td>Post-operative documents</td>
<td>Post-operative documents- 8 (21%) records had any indicators evident</td>
</tr>
<tr>
<td>Discharge documents</td>
<td>Discharge documents – 6 (15%) records had any indicators evident</td>
</tr>
</tbody>
</table>

4.2 Overt Indicators & Demographic Data

Association existed between the evidence of overt participation indicators through the care trajectory and the greater number of previous birth experiences and/or being a public patient. Across all variables, as the consumer preceded through the healthcare trajectory a significant and consistent reduction in evidence of overt indicators occurred.

4.3 Overt indicators and documentation style

The record audit identified that medical clinicians dominated the pre-operative documentation, the doctors were meticulous when describing discussion, options and the consumers ‘request’ for elective surgery. However this was the extent of the overt participation indicators, the same rigorous detail was not applied to the remaining care trajectory. The post-operative and discharge documentation was predominantly directive and clinical within an objective language style. In contrast to medical documentation, midwifery documentation was nominal.

4.4 Documentation Deficiency and Legibility

<table>
<thead>
<tr>
<th>Description</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>High degree of interrater reliability of the audit data demonstrated.</td>
<td>Acceptable documentation legibility</td>
</tr>
<tr>
<td>The range and variety of methods to document and the haphazard filing system, were barriers to tracking care provision</td>
<td>The obstetric early discharge program documentation comprehensive.</td>
</tr>
<tr>
<td>Documentation deficiency evident in the day of admission pre-operative and post-operative clinical pathway.</td>
<td></td>
</tr>
</tbody>
</table>

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Site C Medical Record Domain Summary

The audit findings identified that indicators of consumer participation within the 39 record samples were generally medical clinicians transcribing the processes of obtaining informed consent. Out of the 117 potential opportunities throughout the continuum of care to document consumer participation, be it either implied or overt, only 53 of these opportunities were capitalised on, whilst conversely 64 opportunities were overlooked or not recorded.

The audit identified that not surprisingly, consumer participation indicators were more likely in the pre-operative (100%) rather than postoperative (21%) or discharge (15%) documentation. Overt participation indicators were associated with the consumer demographic variables; greater number of previous birth experiences, public patient.

The validated documentation deficiency audit methodology acknowledged that the diversity of documents (numerous pathways, multiple computerised printouts) and the adhoc filing manner obstructed the researcher throughout the record review. Once consecutive documentation was tracked down, medical documentation was adequate post-operatively and at discharge. However pre-operative documents were in disarray, with both medical and midwifery clinician’s records incomplete and the anaesthetic report was also inconsistent in completeness on a number of dimensions. In contrast the early discharge documents included collaborative and comprehensive documentation.