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Margaret I. Jamieson
University of Wollongong

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A study into the use of and need for healthcare services, for HIV
infected people, from diagnosis until death.

A thesis presented in partial fulfillment of the requirements for the
degree of
Doctor of Philosophy.

from

University of Wollongong

by

Margaret I. Jamieson. BA(Glas.C.T) MPH (Dundee).

Department of Public Health and Nutrition.

1995.

I hereby declare that I am the sole author of this thesis. This thesis does not incorporate without acknowledgement any material previously published or written by another person except where due reference is made in the text.

Margaret I Jamieson.

ABSTRACT

The aim of this study was to determine the use of the healthcare system by people with HIV /AIDS, and to identify and compare variations in service provision to patients with similar needs, and variations between needs and service provision. The variations would suggest changes in service management in the interests of improvements in cost /effectiveness.

Central to health service management is the need for information. The primary hypothesis of this study is that information systems need to be refined to support management of AIDS/HIV as a chronic, infectious condition, from initial manifestation through to death. It is hypothesized that it is impractical to manage healthcare delivery without recognition of the disease processes and changes in social factors over the duration of the disease; or without taking account of the links between episodes of care, and the extent of care management and access.

This was a longitudinal study, which involved two hundred and ninety--two HIV infected respondents. Respondents entered the study through networking, all volunteered. The study duration was from March 1993 until March 1994. In addition to these recipients of care, interviews were undertaken with service providers. This information was used to corroborate the findings of those persons who were HIV infected. Although limited by issues such as volunteer bias, small numbers and an inability to access clinical records, the study produced much useful information. It was possible to ascertain health service utilization for a group of individuals who exhibited a wide range of symptoms. The study also demonstrated the difficulties of accessing a heavily researched group and in maintaining contact over a long period of time. The patient population was highly mobile

in seeking and accessing healthcare. This mobility is reflective of the problems of confidentiality, unmet need within an area and patient choice.

The main findings of the study demonstrated that people sought healthcare from a wide variety of sources. There was considerable use of voluntary and statutory services. Service utilization was influenced by specific demographic features such as living alone, being a professional and using a private physician and/or general practitioner as their main source of care. A series of ten levels of HIV infection, from diagnosis through to death, were identified. The levels indicate increasing disease severity and increasing healthcare needs. One trend from this study suggests that the bulk of care is happening in the community with a heavy involvement of voluntary carers. The involvement of a significant number of agencies in the delivery of care impacts upon costs and co-ordination of care. There are substantial costs involved including personal costs that were beyond the scope of this study to evaluate. Whilst the use of Diagnosis Related Groups is applicable to the estimation of hospital costs, given the trend towards community care, it is important to develop a series of cost measures that incorporate community as well as hospital costs.

The findings of the study suggest that there is an urgent need to develop a structured approach to co-ordination of care. A development of a series of cost measures that incorporate community and hospital cost is required. Whilst there is no such thing as a typical patient, it is possible to identify a series of phases of HIV infection with levels of severity. Each stage indicates a differing need for and use of healthcare services. The importance of collecting demographic data was reinforced. It was possible to show that for this group of HIV infected people, certain factors, were implicated in the frequency and use of healthcare services. The need for additional services was brought to the fore, particularly services relating to specialized home care and community psychiatric support.

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Chapter 1: Introduction

Acquired Immune Deficiency Syndrome (AIDS) was first defined in 1981 as a constellation of symptoms in patients who presented with rare opportunistic infections such as Kaposi's sarcoma (KS) (Centres for Disease Control, 1981; Gottlieb et al, 1981). Diseases usually only seen in immuno-compromised individuals were suddenly appearing in record numbers of homosexual men with no known underlying cause for immune dysfunction (Gottlieb et al 1981). In 1984, scientists announced that the Human Immuno-deficiency Virus (HIV) was the putative causal agent. Retrospective studies suggest that the virus originated in Africa and was present there at least by 1959 (Nahamias et al 1986), that it was in America by 1978 (Centres for Disease Control 1982) and from there (and possibly from Africa as well) (Bygberg, 1983; Vandepitte et al 1984) spread to Europe by the mid 1970s and Australasia by 1982 (National Health and Medical Research Council, 1984). AIDS has now been defined as an advanced state of HIV infection, which is fatal (Ross 1994).

Since 1991, AIDS has become known as a state of immuno-suppression in which an HIV infected person's CD4 lymphocyte count has fallen below 200 cubic millimetres (CDC, 1991). This change recognizes that HIV disease is a spectrum of illness. The vast majority of HIV infected people are asymptomatic and not severely immuno-compromised. HIV has proved to be a fast moving target, able to mutate its structure to elude detection, drugs and vaccines. AIDS is a modern epidemic caused by an agent that was not isolated until 1983 and which did not appear outside of Africa until the 1950s. It is, according to Ross (1994:323)

"A new epidemic in both historical and virological terms, and its spread appears in part to reflect the new conditions which have lead to altered patterns of disease namely: greater mobility through international travel, changes in sexual and drug using practices, and population movements and their associated dislocations and relocations."

The epidemiology of AIDS /HIV can be viewed as reflecting social and historical change in the latter half of the twentieth century (Ross 1994). It is a spectrum of disease that is always fatal and to date has mainly affected those persons who are in their economically productive years. The human and social costs of this disease are far reaching and have the potential to be catastrophic in some parts of the world, particularly developing nations where economic and health care development would be severely constrained. The World Health Organization has estimated that by the year 2000 at least 30 million people will be infected with the virus.

The variable progression of HIV infection makes it difficult to estimate the impact on the health care resource. Traditionally, health services have been difficult to manage due to the constant flux in medical and surgical conditions and the responses to them. HIV is a unique example, which demonstrates the difficulty in predicting the demand for care, largely due to the nature of the disease, its multiple presentations, the variable incubation period, and the indications that some groups are more susceptible than others (Chin & Mann 1988). At present there are insufficient data on which to make accurate predictions of healthcare use. In Australia this is compounded by the small data pool. World-wide there is a lack of information about the needs of those persons who are HIV infected, and their need for and use of healthcare services.

Although scientific knowledge about the aetiology, epidemiology and clinical management of AIDS has grown at an exponential rate, much remains unknown. Many questions remain, not least how to quantify the need for health care, from the point of diagnosis of HIV infection, through the development of AIDS and finally to death. It can be argued that AIDS is causing a traumatic change in healthcare use and expenditure. In Newark (USA) it is estimated that use of the healthcare services (county hospitals) has risen by 60% in the past 2 years, in caring for people at varying stages of HIV infection. This pattern is being replicated throughout the major sites of HIV prevalence in the USA (Rees, 1991). Glick and Stern (1991) estimate that 30% of funding in the US public system is now being

directed towards HIV and AIDS care. However, estimation of the need for health care resources has concentrated upon the determination of the levels of need of people in the final stages of the illness, that is those with AIDS. Models used in the planning of health care services have based their estimates on back-projections of figures, yet this will be flawed due to the reliance upon figures relating to AIDS patients. Whilst knowledge of the spectrum of the illness caused by HIV has broadened, much remains unknown. In 1988 the United States Presidential Commission on the HIV epidemic stated:

"The term AIDS is obsolete. HIV infection more correctly defines the problem. The medical, public health, political and community leadership must focus upon the full course of HIV infection rather than concentrating upon the later stages of the disease (ARC&AIDS). Continual focus on the later stages of the disease rather than upon the entire spectrum of HIV infection has left our nation unable to deal adequately with the epidemic" (p18).

The social cost is enormous. In developed nations, AIDS has struck the "productive" element of society, those aged 20-40 years. In Australia, the average age of persons dying of AIDS is 38 years (Kaldor et al 1992). In developed nations, such as the United States and Australia, AIDS was mainly a disease of minorities, for example, injecting drug users and homosexual men. However, it is estimated that worldwide by the year 2000 women will equal the number of male carriers of HIV (Johnson & De Cock, 1994). At present women account for 36% of an estimated 12.9 million infections world-wide (Johnson & De Cock, 1994). The implications for increasing the population infected through childbirth and the resultant effects on social stability are enormous.

By March 1992, in Australia, there were 16,147 cases of HIV infection recorded by the National Centre in Clinical Epidemiology and Research. The incidence of HIV infection reached a peak during the years 1983 to 1984 and declined rapidly thereafter (McDonald et al 1994). However, the figures were calculated using a back-projection method on the number of cases of AIDS, this means that it is difficult to estimate the current rate of HIV

infection in the Australian population as it will be difficult to determine how many cases will have progressed to AIDS. The variance in time from being infected and asymptomatic until becoming symptomatic is different for each infected individual. Consequently, the use of the healthcare system is different for each person depending upon their symptoms and their social support systems. Unlike any other infection HIV is multi-faceted in its presentations and effects. There is a need to describe the impact upon the infected individual and the healthcare system, in order to effectively react in terms of care provision.

The purpose of this study is to describe and measure the use of, and need for, healthcare services in relation to the various phases of HIV infection, from the point of diagnosis to the development of AIDS. Because of the nature of the disease, it seems appropriate to describe over time, the impact of the disease on the persons infected and their use and need for health care services. The collection of such data will be retained in a database format that will assist in the description of resource use correlated with disease progression.

1.2 Origins of the research

This study was designed to address a widespread concern regarding people with chronic health problems who require care in many settings over prolonged periods: that their needs may be inadequately understood, and that the care they receive might be inappropriately fragmented. In recent years, increased emphasis has been given to the refinement of information concerning modes of care which occur in a single setting and particularly to acute inpatient episodes. While there has been a continual process of stressing the importance of continuity of care for persons with chronic conditions, there has been hardly any significant improvement of practice.

There are several chronic diseases (such as diabetes, multiple sclerosis and HIV/AIDS) which consume a significant proportion of health care resources, and which are associated with serious dysfunction and high mortality rates. There is evidence to suggest that none is

being adequately addressed in management terms. Indeed, there is reason to believe that management is deteriorating in some respects as a consequence of continued clinical specialisation and orientation of information systems towards facilities rather than people.

The experience of the author in health care, at a clinical and managerial level, reinforced the problems of care management. In particular, internal politics within organisations are not always helpful in the provision of care, as highlighted by the comment by a leading medical specialist when discussing HIV/AIDS "whose virus is it ?" (Silverman, 1990:193). The vying for power and resources has long been a struggle in healthcare provision, both internally within the healthcare system, and externally at a macro/governmental level. How resources are allocated is an other area which does not, in the experience of the author, always equate with any form of rational planning. Whilst recognising that the path to the development of AIDS policies has been a long and involved process, due in no small part to the conflicts between competing interests, the question arises how well the needs of those individuals with HIV/AIDS are served by the health care system. Need is a difficult concept to define and subsequently assess. Operationally, demand is often employed as a proxy for need in health care provision. This approach has been criticised by Buchan et al (1990) as failing to accurately reflect the real need for services, and specifically for those with AIDS/HIV (Warren & Bebbington, 1990).

Whilst not unique in terms of management and allocation of resources, HIV/AIDS is an ideal example of the problems. Considerable management research has been undertaken, but much has focused on discrete stages. For example, the Commonwealth and several State governments have funded research under the Casemix Development Program which has almost exclusively concerned the costing and classification of acute inpatient episodes. While there may be some benefit in more precise understanding of acute inpatient phases, there are also some significant risks. For example, it would serve little purpose to facilitate better management of acute inpatient episodes by use of DRG-based funding, if most of the

episodes could have been avoided by better monitoring and improved service provision in a community setting.

In summary, efforts may be needed to redress the balance. They can take many forms, including the kinds of political commitments contained in the National Health Strategy and Health For All. The focus of this research is, however, information relevant to integral management of chronic conditions. HIV/AIDS has been selected, but it is expected that many of the ideas will be of more general relevance.

1.3 Study Objectives

Several approaches might be taken to examine and improve the set of information relevant to management of HIV/AIDS. It was decided, however, that the primary objective would be the development of a model which might support improved methods of resource allocation regardless of setting.

During the initial stage of formulation of a research plan, several sub-objectives were identified, which may be categorised as follows.

1 Actual resource use.

To estimate actual levels of health care resource use related to the disease under study, from onset (defined to be at HIV diagnosis) to death (and including the development of AIDS).

2 Needs and demands for health care.

To identify and measure the actual needs for health care, perceptions of HIV/AIDS patients regarding their needs, and demands for health care.

Inter alia, this would involve consideration of the impact of a chronic disease on the individual and the health care system.

3 Interpretation of differences between needs and actual service provision.

To identify differences between the needs for and provision of care; and to analyse factors potentially relevant to the differences including social, geographic, demographic and time variables.

Inter alia, this would require consideration of aspects of current management, including the degree of coordination of services as perceived by both recipients and providers of care.

4 Model construction.

To develop a model for classification of patients according to health care needs and health care provision.

In summary, the key inputs to the model were expected to comprise data derived through surveys of health care provision and need. These would need to be related to social and clinical indicators of patients' conditions over the entire duration of the illness. Therefore the study database would need to comprise a set of records, each of which represents a person. Each record must include identifiers; and periodic measures of clinical status, care needs, and service provision. It would then be necessary to analyse the database to identify variations in service provision to persons with similar needs and variations between needs and service provision.

The key output of the research was expected to be a model which explained variations in needs for and provision of care according to clinical attributes.

1.4 Formal statement of the research hypotheses.

The primary hypothesis is that patients with AIDS/HIV can be classified by clinical measures, in such a way that their care needs and actual resource consumption can be predicted.

It is useful to identify three subsidiary hypotheses, each of which needs to be tested during the course of research.

- 1 Classification must define AIDS/HIV infection as a chronic, infectious condition, and each class must define care needs from initial manifestation through to death.
- 2 Use of the health-care system can be explained in terms of measurements of disease status.
- 3 Measurement of actual and perceived needs, and comparison of needs and actual service provision, will demonstrate those areas of service deficiency.

In other words, measurement of need compared against service provision should result in a series of measures for future service planning. The variations recorded between need and service provision would suggest changes in service management in the interests of improvements in cost/effectiveness.

1.5. Thesis Structure.

Throughout this thesis the term AIDS refers to the AIDS epidemic as a broad social, medical and cultural crisis. The terms HIV diseases, AIDS and HIV infection are used interchangeably to mean the broad clinical spectrum of HIV related conditions from asymptomatic infection to specific diseases presently used to define AIDS. The term AIDS is used to mean the inclusive medical spectrum only if this sense is clear in context.

For ease of presentation each chapter commences with an overview of the main contents of the chapter. Chapters two, three and four are a review of the literature. Chapter two deals with the biological, epidemiological and clinical presentations of AIDS/HIV and suggests that in order to effectively clinically manage the range of diseases, there requires to be some form of structured approach taken such as case management. In chapter three, the focus shifts from a concern with the physical properties of the disease, to the representations of the disease in its short history and the types of policy formed as a result of these perceptions. Whilst not the main focus of this thesis, this chapter was deemed necessary, as it places in context the social and political backdrop against which health care services are accessed and delivered. Consequently it brings to the fore some of the issues, such as discrimination (conscious and unconscious) by health professionals and the rest of society as well. Views on homosexuality and "who deserves care" are inextricably linked and affect policy formation and the subsequent delivery and availability of health care. This chapter serves to highlight some of the potential barriers to the provision and subsequent accessing of health care at both the individual and policy levels.

In chapter four the problems of healthcare access and the measures used thus far to estimate healthcare use and cost are discussed. From the literature, it is apparent that estimates of healthcare use and cost have largely been determined by the estimation of costs of AIDS, not from the time of diagnosis as being HIV infected through to AIDS and eventually death. Estimation of costs and need for care have been carried retrospectively, yet knowledge about AIDS and its treatment are constantly evolving, consequently it seems inappropriate to planing of future care needs on what happen in the past as this may not be appropriate to the changing nature of the disease and its treatment.

Chapter five describes the study design, the method of study, the participants and the setting in which the study took place. This was a longitudinal study, which used purposive and convenience sampling. Data was collected from two different groups of participants, the

providers of care and the recipients. Data was collected from providers by interview and from recipients by questionnaire. It was recognised that undertaking a longitudinal study with a group who had been heavily researched would be problematic. However, a longitudinal study by its very nature can demonstrate change over time and has, as noted by Seed (1995), the obligation to reflect the difficulties of undertaking research using a longitudinal design. Chapter six describes the findings from the prospective pilot study and demonstrates that this method was appropriate in tracking individuals over time and obtaining useful data. The pilot highlighted that there were areas of unmet need in relation to the provision of care especially to minority groups and that there was a need for community psychiatric care and social care, particularly housing and financial assistance. Coordination of care was problematic from a professional viewpoint. It was noted that people with HIV/AIDS sought care from multiple care sites often based on personal networking. It is important to note that the HIV infected participants from the pilot study were used as part of the main study, the results of which are contained in chapter seven. Chapter eight does not have an overview as it is the discussion of the results. The study limitations, areas for further research and the study conclusions are also contained in chapter eight.

Chapter 2 : The Nature of AIDS / HIV Infection.

Overview.

This chapter discusses the **nature** of the modern epidemic Acquired Immune Deficiency Syndrome (AIDS). This is a fatal syndrome which is thought to be caused by the Human Immunodeficiency Virus (HIV) and the clinical syndrome may occur many years (on average 8-10 years) after the initial infection. The agent generally accepted as causing the syndrome was not isolated until 1983 and there is a great deal of controversy surrounding the discovery and the nature of the virus. The presence of the virus was detected following the notification of a rising incidence of a rare cancer, Kaposi's sarcoma, amongst homosexually active men in North America.

Transmission of the virus is through the exchange of body fluids such as blood, semen and breast milk. The most efficient route of transmission is via direct injection or transfusion of blood.

There are differing **global patterns of transmission**. In Sub-Saharan Africa (where the World Health Organisation estimates that more than 10 million people are infected), spread has been through heterosexual transmission, particularly along trade routes. In North America, northern Europe and Australia, spread has been predominantly amongst homosexually active men. In Southern Europe, the spread has largely been among Intravenous Drug Users (IDUs). The virus found its niche in a climate of changing social factors such as: advancing poverty and hence the spread along trade routes in India and Africa; through prostitution; changing sexual mores; changing social attitudes towards drug use and the rise in "sex tourism" particularly in Asia.

After initial infection, seroconversion occurs. The latency of the disease and the types of manifestations are reliant on a number of co-factors, such as the presence of other disease.

The time frame for the development of AIDS is dependant upon a host of factors, unique to each individual, but there can be anything up to ten years prior to significant symptom development.

HIV infection in Australia has most affected "men who have sex with men" this encompasses a larger group than just those who identify with the gay community. There is spread amongst the IDU population and thus heterosexual spread, although this has been largely contained due to the progressive policy of needle exchange. In Australia, there is a degree of concern about the level of spread through the popularity of sex tours to areas such as Thailand and other parts of Southeast Asia.

Clinical management of the disease is an area which is controversial. In the same way as the origins of the disease are subject to debate, so too are the drugs employed as treatment. There is discussion on the use of anti-retrovirals and other therapeutic regimes currently employed. Treatment, and indeed detection of the disease, are hampered by the variance in time after seroconversion through to exhibiting symptoms of infection. Some individuals may be asymptomatic for a period of up to 10 years, whilst others manifest disease and die in a short period of time.

The **range of HIV infection** is indicated by diseases such as: Pneumonia Carinii, Pneumocystis (PCP), multiple infections and wasting syndrome. There is debate in the scientific literature as to whether some of the current treatments do prolong survival time, or whether these treatments are themselves harmful. This is particularly true for the drug Zidovudine (AZT). Professor Ian Weller (1993), Chairman of the Anglo-French Concorde Study of AZT noted: "What we've seen as a result -not only of Concorde, but of recent trials in the US-is that it's dawning on people the [AIDS] drugs we have are not that useful".

An issue that is of prime importance is the use of some form of **case management** by a health care professional. Case management enables access to services, coordinating of

services and resource control. This has been included as part of the medical management as the medical practitioner, whether General Practitioner or Specialist has the potential to play a crucial role in the provision and delivery of services for those who are HIV infected.

This chapter describes the nature, transmission and groups most affected by the disease. The complexities of medical management, due to the constant evolution of knowledge about the disease and its subsequent treatment are touched upon. The need for a structured approach, in the form of case management, will be outlined, and whilst this approach has been described under the umbrella of medical management, it is not the sole prerogative nor responsibility of medical practitioners. Other groups and health care professionals have an equally important role to play.

Chapter 2 : The Nature of AIDS / HIV Infection.

2.1 The Nature of AIDS / HIV Infection.

Acquired Immune Deficiency Syndrome (AIDS) is a spectrum of diseases caused by the virus called Human Immunodeficiency Virus (HIV). The virus was isolated in 1983 (Barre-Sinoussi et al 1983) and called LAV-1. Subsequently, a similar virus was isolated by Gallo (1985) who described it as HTLV-111. It is worthwhile to note that the discovery of the virus which causes AIDS was shrouded in controversy. The American team under the leadership of Dr R Gallo were rivals of the team working in France at the Pasteur Institute. However, it was the French researcher, Jean -Claude Chermann, who first delivered a paper describing the virus at a scientific conference in Park City, Utah, on February 7th 1984 (Shilts, 1987). From the beginning AIDS was (and is) a controversial issue, even the biological origins of the virus were the cause of dispute.

HIV is classified as a retrovirus. Retroviruses are so called because they reverse the usual flow of genetic information within the host cell (Carr ,1992). Like all viruses HIV is simply a strand of genetic material (in this case the nucleic acid, RNA) surrounded by a protein coat. A virus lacks the tools to reproduce unless it invades a living cell and takes over the host's molecular machinery. The intruder can then produce many copies of itself, eventually killing the cell. HIV has a particular predilection for the CD4 T-CELL, (T-helper cells), an important component in the human immune system (Matlow & Fisher,1988).

Carr (1992:5) stipulates that "any disruption in the functioning of the T-helper cells disrupts the entire cellular immune system and thereby causes immune deficiency. It is when T-helper cells are activated, when they begin to issue messenger RNA commands for the construction of proteins, that they activate the HIV genetic codes which are lying latent in their nuclei. The activated T-helper cell becomes a factory for making new HIV particles."

HIV does not infect all the T-helper cells, if cells lack the receptor (CD4 molecule) then they cannot be infected (Weber, 1988) and it does not kill all the cells which it infects.

However, HIV infection does lead to the destruction of a large and increasing proportion of the infected person's T-cells. According to Weber (1988) it is when the virus replicates, it appears to cause a degree of toxicity in the cell involved and to cause premature senility in the cells that are infected. Such cells die early, and it is the loss of these cells that leads to the disease known as AIDS and other related phenomena. Carr (1992) discusses the fact that infected cells exhibit certain proteins which cause many uninfected cells to bind to them, forming clumps, called syncytia, which eventually die. Cells with latent HIV infection display certain viral proteins which cause them to be attacked and killed by other parts of the immune system. Infected cells secrete a viral protein called gp120, which clings to uninfected cells and causes them also to be attacked by the immune system (Weber, 1988).

It is by these routes that HIV infection leads eventually to the disappearance of the T-cells and the onset of immune deficiency. A healthy person has a T-cell count of 800 per cubic millimetre (normal range = 500-1200). HIV infection eventually causes the T-cell count to fall below 400, at which time the person may begin to develop symptoms of HIV related illness.

According to Matlow & Fisher (1988), when the T-cell count falls below 200, the individual is vulnerable to the major opportunistic infections and cancers which define AIDS:

Pneumocystis carinii pneumonia (PCP), Kaposi's sarcoma (KS), mycobacterial infections (MAI and tuberculosis), Herpes virus infections, rare infections of the brain and gastrointestinal tract, and cancers of the lymphatic system and the brain. It is the frequency of occurrence and combination of these infections and cancers which prove fatal.

The T-cells are not the only cells which HIV infects. Other cells of the immune system, such as macrophages and monocytes, may also be affected, further disrupting the immune

system (Geddes, 1988). It has been postulated that some HIV infected cells produce cytokines, which are toxic to the T cells thus hastening their decline. In addition, HIV is thought to directly infect cells in other parts of the body, such as the gastrointestinal tract and the central nervous system. HIV related neurological illness can be caused by the direct activity of HIV or by opportunistic infections. Pathogenesis of HIV disease following infection is still unclear. However, there are three ways in which HIV causes disease *in vivo*:

- (1) primary HIV effect -- lytic action on infected cell;
 - (2) secondary opportunist infections-- e.g. CNS toxoplasmosis;
 - (3) opportunist tumours-- e.g. CNS B cell (Burkitt - type) lymphoma
- (Weber, 1988:8).

But there the understanding of nature of the virus runs out. It is not known why HIV lies dormant in human cells, usually for years, before producing AIDS. What triggers the final phase of the infection and how the virus destroys the immune system are as yet unknown. Even at the height of the disease, HIV particles are found in no more than 1 in 100 CD4 T-Cells. Yet the cells that do not harbour the virus die off as quickly as those that do. It is thought by some that HIV must somehow provoke immune system cells to destroy themselves. It is important to note that development of AIDS takes many differing presentations, from dementia to Kaposi's sarcoma, to varying forms of pneumonia, thus making case definition difficult (Carr, 1992). The extent of the involvement of HIV as a causal factor in AIDS is the source of much scientific debate. In a editorial in Nature, Maddox (1992:189) commented "[Luc] Montagnier said clearly what he meant, HIV is a necessary but not, without the co-factor, a sufficient cause of AIDS".

Duesberg (1989) argues that HIV is not the cause of AIDS. He asserts that HIV does not have the physical properties to cause the disease, nor the pathology of AIDS. The depletion of CD4 cells, according to the authors of another study, does not cause AIDS, it is caused by HIV infection, dysfunction, and the ultimate destruction of the cells that present the intracellular microbes that cause opportunistic infections to the CD4 and CD8 cells (Giannetti, Zambruno, Cimorelli, et al. 1993; Langhoff, Haseltine, 1992). When infected, these antigen presenting cells can no longer appropriately activate CD4 and CD8 cells to begin to proliferate and form additional helper, effector and memory cells (Mactonia, Patterson, Knight, 1989). The end result of this continual decrease in the total number of T-lymphocytes is an impaired immune response and progression to AIDS (Janeway, 1992).

It would appear that as research develops, then the knowledge of the nature of the HIV virus, and the spectrum of diseases called AIDS will also evolve. Controversy surrounds this spectrum of disease from its origins to its treatment. It is beyond the scope of this thesis to adequately discuss the scientific arguments surrounding HIV and AIDS, but their importance is acknowledged.

2.2 Transmission of the Virus

The world-wide epidemic of HIV is largely monitored by the surveillance of persons diagnosed with its most advanced manifestation--AIDS (World Health Organisation, 1992). To date, there are two definite types of HIV which have been described: HIV-1 and HIV-2. The latter has been implicated as a causal factor of AIDS in Africa (Clumeck et al 1984; Piot et al 1984; Clavel et al.1986). HIV can be transmitted from person to person in only 3 ways, as follows:

(a) via sexual intercourse (vaginal or anal) (Fauci et al, 1984; WHO 1987)

(b) By injection or transfusion of HIV infected blood, blood products and semen; by contact with HIV infected tissue or organs; or by sharing drug injecting equipment (Infectious Disease Society of America, 1986; WHO,1987)

(c) from a mother to her foetus /infant (peri-natal transmission) (IDSA, 1986; WHO 1987).

Each way involves exposure to infected body fluids, such as semen, vaginal secretions and blood, or to infected tissues or organs. There have been other reported routes of transmission, all involving the exchange of infected body fluids (Ziegler et al 1985; Kristal et al 1986). The main route described is from child to mother during breast-feeding (Van de Pierre et al 1991), through cracks or sores in the child's mouth and on the mother's nipple. Infection does occur *in utero* (Almond and Ulanowsky 1990). According to Chapman (1992:128), the sexual transmission of HIV can be described in three stages as follows:

Table 2:1: Sexual transmission of HIV.

Primary (1st generation)	HIV is acquired through sex with infected individuals; needle sharing and from contaminated blood products.
Secondary (2nd generation)	Primary HIV carriers infect persons not in the primary risk category. This group encapsulates the sexual partners of bisexual men, injecting drug users and those persons who were in receipt of infected blood products.
Tertiary	HIV is transmitted from a seropositive person who is not in any primary risk group (ie from a secondary case)

[Source: Chapman S "Dogma Disputed" *Aust J Public Health* 1992; 16: 128-41.]

HIV transmission is predominantly via sexual intercourse. This appears to be the most efficient route, although the probability of an individual being infected depends largely upon the probability of being exposed to the agent that causes the disease. It has been postulated that the presence of other conditions and trauma at the site of intercourse assist transmission of the HIV virus (European Study Group, 1989; De Vincenzi & Ancell-Park 1991).

The transmission of HIV has been linked with other sexually transmitted diseases, although it remains unclear whether this is because all these infections co-exist, or whether the existence of another sexually transmitted disease increases the efficiency of HIV transmission (Chin & Mann, 1988; Pokrovsky et al., 1989). Mertens et al (1990) have demonstrated that the existence of sexually transmitted diseases which cause ulceration of the epithelium, such as syphilis, chlamydia, herpes and chancroid increase the efficiency of

HIV with exposure. Cameron et al (1989) and Kreiss et al (1989) discuss the presence of genital ulcer disease as a co-factor. This form of transmission is relatively efficient; lymphocytes are the major source of HIV in cervico-vaginal secretions of infected women.

Padian (1990) states that following exposure to an HIV infected person there are various factors which will have a bearing upon the probability of transmission occurring. These include: sexual practices (penile penetration of the vagina or anus), the resistance of the host, the stage of the disease in the carrier, and the presence of sexually transmitted disease co-factors that facilitate transmission. It is interesting to note that work by Johnson et al (1988) and Padian et al (1988), demonstrated that there is a poor correlation between the numbers of exposures and infection. In the six-nation European study of 153 HIV infected men and their 155 female sexual partners, reported in 1989, it was found that 27% of the women were HIV positive. These women did not have any other risk factors, apart from being the sexual partner of an HIV positive man. The study reported that there were three facts which appeared to increase the risk of transmission in the women: previous infection with a sexually transmitted disease, in the past five years; the man having AIDS; and the practice of anal intercourse. The length of the relationship and sexual practices, other than anal intercourse, were not significant factors.

Blood borne transmission and the transfer of the virus via serum containing tissue is, according to Klein and Friedland (1990), a most efficient route and one which will occur in both the medical and non medical situation. Crofts (1992:30) states that: "the efficiency of transmission depends upon many, mostly unquantified, factors, including the infectivity of the donor, the immune status of the recipient, the infectious dose, the route of exposure or injection, and so on."

Donations of whole blood and of Factor VIII (the product used for haemophiliacs, to assist their clotting mechanisms), tissue and organ donations and Human Immunoglobulin have all been implicated in the transmission of HIV. Since 1985, in developed countries there has

been a universal screening of the donors of blood and organs. It is notable that in Queensland in 1984 three babies died following transfusion of blood from an infected donor (Landsell 1991).

In resource-poor countries such as the developing nations of Africa, the Caribbean and the Indian subcontinent, the re-use of nonsterilised needles for orthodox or non-orthodox medical therapy has been implicated as a mode of transmission. For example, in Haiti, the government estimates that there are between 12,000 and 15,000 *pirouistes*; lay people who give injections as part of a healing process in the population (Chin & Mann, 1988). This has obvious implications regarding the spread of AIDS. Indeed Haiti and the Caribbean was initially thought to be the source of infection entering the USA (Shilts, 1987; Ross, 1994).

Transmission by the exposure of health-care workers to contaminated blood or other infected body fluids has been infrequently reported, as has transmission by exposure of patients to infected health workers. The adherence to universal precautions as advocated by the CDC (1987) when dealing with infected materials should protect all parties involved. There have been calls to test individuals prior to surgery (Breo, 1987; O'Connor 1990; Scannell 1989), arguments proffered have included the possible effects on surgery; the opportunity to screen for HIV and the prevention of transmission to healthcare workers.

The use of contaminated needles by injecting drug users remains a problem in both developing and developed countries. For example, in Thailand, Vanichensi et al (1989) reported upon the prevalence rates amongst injecting drug users. It was found that needle sharing was the main documented risk factor and the authors reported that seroprevalence rates were up by 20% within a two year period. A similar pattern was reported upon in Northern India by Naik et al (1991). It was thought that this outbreak was as a result of an increase in the levels of heroin available and Burma was implicated as the source.

In the USA, spread amongst injecting drug users is strongly linked with race and poverty (CDC 1986; Hahn et al 1989; Mendez et al 1990). The prevalence of "shooting galleries " is a crucial risk factor in the sharing of needles (Chaisson et al 1987; Des Jarlais & Friedman 1987; Battjes et al 1989; Hahn et al 1989; Chitwood et al 1990).

In Europe and Australia the main risk to injecting drug users is the use of shared needles. Interestingly a study conducted in Melbourne by Denham & Hayes (1990) found no increase in seroprevalence between the years 1986-89. This would appear to suggest as do studies from the USA and the UK (Sorensen et al.,1988; Skidmore et al.,1990) that the level of risk through the use of shared needles has changed. The study by Skidmore et al.(1990) suggests that the increased use of bleach may also be an important factor. In Edinburgh where the spread of AIDS is greater than in the similar city of Glasgow, the difference in spread is thought to be directly related to the different policies adopted in the two cities. In Glasgow there has been an open policy regarding needle exchange whereas in Edinburgh there was a reluctance on behalf of the "city fathers" and the local police to adopt needle exchange and education programmes (Robertson 1990). It could be argued that the repressive attitude in Edinburgh, in effect, actively encouraged the explosion of AIDS within the drug using population (Brettle & Wattle 1991). Needle sharing does occur in Glasgow (McKeganey et al 1989), but not to the same extent as in Edinburgh (Robertson et al 1986).

Vertical transmission from mother to foetus, according to Crofts (1992), occurs with approximately 35% efficiency. Two studies reported in 1991 (Ehrnest et al.; Modlin & Saah) estimate that the efficiency of transmission varies from between 10%-70%. The range is so varied, according to the authors, because of the difficulty in obtaining a true diagnosis of HIV infection due to the presence of maternal antibodies in the blood-stream of the infant. The authors of these studies went on to suggest that the peri-natal transmission rate may be proportional to the level of maternal HIV infection: the greater the level of maternal infection the greater the risk to the foetus of being infected. Vertical transmission

definitely occurs post delivery from breast feeding (Cutting 1993). This has wide reaching implications in countries where heterosexual spread is dominant.

Prostitutes are a group who according to Cohen (1989), have been made "scapegoats " in the transmission of AIDS. They have been viewed as a reservoir of infection threatening others. McKeganey and Barnard (1992:115) state that "this perception is greater for female prostitutes than for male prostitutes, though for no better reason than that our ignorance of male prostitutes is so great that even such prejudicial attitudes have not really had the scope to develop."

There is no consistent global pattern in the association between prostitution and AIDS (Padian, 1988). In sub-Saharan Africa, prostitution appears to have played a significant role in the spread of HIV infection (D'Costa et al 1985; Piot et al 1987). In Europe, Australia and North America, prostitution does not appear to be a significant player in the transmission of HIV (Cohen et al 1989; Chaisson et al 1990). In some North American cities there has been a demonstrated association between the use of crack cocaine and high risk sexual behaviour (Golden et al 1990; Weisseman et al 1990). Similarly, particular concern has been expressed with respect to individuals who use prostitution to finance a drug habit (Henderson, 1992). Raised levels of HIV infection have been identified among female drug injecting prostitutes as compared to non-injecting prostitute women (Tirelli et al 1989).

It is apparent that the transmission of the HIV virus necessitates the correct conditions being available to the virus, the exchange of bodily fluids, exposure to contaminated instruments and the individual participating in behaviours which will increase their risk, ie male to male unprotected sex, or indeed unprotected sex with any individual who has been exposed to the virus from whatever source. As with any infectious disease, "{t}he probability of an individual being infected will depend on the probability of being exposed to the agent that causes the disease" (Chapman, 1992:136).

2.3 Disease Progression.

After being infected with HIV, 30-60% of people will manifest seroconversion. The illness presents with a combination of fever, myalgia, night sweats, headache, diarrhoea, mouth ulcers, oral candidasis and /or sore throat lasting 1-3 weeks (Tindall et al.,1988).

After the acute infection, symptomatic or asymptomatic, an infected individual will remain symptom free for a variable period of time. This latent period on average lasts about 8 years, during which time the person does not require treatment. There is some empirical evidence that the incubation period for AIDS is lengthening (Taylor et al.,1991) and could now be in the magnitude of ten years. Estimates on the progression rate have been made from large cohort studies (Brookmeyer & Goedert et al.,1989; Bacchetti & Moss, 1989) and from surveillance data on medically acquired HIV (Kalbfleisch &Lawless, 1989). Becker et al.(1993) report that the estimates of the progression rate are now "quite good" up to about six years after infection. Figures are not readily available beyond 10 years due to the fact that the epidemic has been monitored for little more than the ten year period and, according to Brookmeyer & Liao (1991), it is estimated that some 50% of individuals may have an incubation period longer than 10 years. The estimates from the cohort studies can be summarised as follows:

Number of years after infection	% (cumulative) who have developed AIDS
2	< 2
4	5-10
6	10-25
8	30-40
10	approximately 50

(Moss & Bacchetti, 1989)

These data from cohort studies are matched by indications from mathematical models which suggest that before the advent of therapies such as zidovudine, the mean incubation period from infection to AIDS was 8-10 years (Lui et al.,1988). The cohort studies also suggest that most infected persons will progress to AIDS but up to 25% remain healthy after 12 years in some studies. It would appear that as more data become available there will be greater precision in the estimation and prediction of the latent period.

The concept of the latency period is not beyond dispute. The researchers Pantaleo, Graziosi and Fauci, from the Laboratory of Immune Regulation, National Institute for Allergies and Infectious Diseases, in the USA, published a paper in February 1994: "The Immunopathogenesis of HIV infection." in the New England Journal of Medicine. In this paper the authors discuss the fact that although HIV infection is characterised by a prolonged period of latency after the initial infection, the virus replicates continually in the lymphoid organs during this period. This would mean that there is damage done to the immune system, during what appears to be the "asymptomatic" stage. The authors point out that the term "clinical latency " is misleading, since during this period all patients will have a gradual deterioration of the immune system, demonstrated through the depletion of the CD4 cells. This work has several implications. Firstly the latent period may not exist as there is in reality a continuous replication of the HIV virus within the body. Secondly, the use of the blood level of CD4 cells to determine the status of the disease may not accurately reflect the true level of HIV infection in the body. It would appear from this paper that the current ability to detect the level of viral activity in the body, using "peripheral blood samples may be an inaccurate measure."(Pantaleo, Graziosi, & Fauci, 1994:328). Hence the latent period may be in reality a period when the individual does not exhibit symptoms and yet there is viral activity occurring. The means of detection would require the use of tests to measure the viral load and activity in the lymph nodes. Whilst this is one paper it does serve to illustrate the fact that knowledge about the virus is constantly evolving. It would appear that there are no absolutes when it comes to the nature of the virus.

The role of co-factors, such as the existence of sexually transmitted disease, in determining and affecting the speed of progression to AIDS in any individual is still unclear. It is suggested that the number of sexual partners is a risk factor (May & Anderson, 1987) for a relatively short incubation period, and there is a faster progression to AIDS for older haemophiliacs (of more than 20 years) as compared to younger haemophiliacs (Goedert et al 1989). A study which has particular relevance to Australia concludes that ultra- violet light may contribute to disease progression (Duvic, 1991). The level of UV-A light needed to activate dormant HIV is unknown.

According to the Centre for Disease Control (1986), Tuberculosis (TB), is the only infection associated with HIV infection which poses a threat to non-immune suppressed individuals. In 1986, there was an upsurge in the number of cases of TB, particularly in the States of New York, Florida and California. Interestingly, the CDC noted that the majority of cases were amongst intravenous drug users (IDUs) and a reactivation of a previous infection. In Africa, the rates of tuberculosis are increasing (Nasrain, Raviglione, & Kochi 1992) and it has become the leading opportunistic infection and cause of death in people infected with HIV (Lucas, Hounnou, Peacock, et al 1993).

2.3 Global Patterns of the HIV Epidemic.

The World Health Organisation's Global Programme on AIDS (WHO:GPA) has described four patterns on a world -wide scale. The following description is taken from the address given by Dr Jonathon Mann, Director of the WHO:GPA : "Global AIDS into the 1990s" as presented at the Vth International Conference on AIDS in Montreal 1989.

Pattern 1: is the pattern common to Europe, North America, Australia and New Zealand. In these countries transmission of the virus has occurred primarily through sexual contact amongst homosexual men, through intravenous drug use and contaminated blood products. The period of extensive spread was from the late 1970s to the early 1980s. It is relevant to

note that the screening of blood products from 1985 has done much to contain this level of transmission. Overall, the prevalence of HIV in the population as a whole is estimated to be around 1%, however, in the homosexual community this may exceed 50%.

Pattern 2: is associated with heterosexual spread and is seen in developing countries in Africa and Third World Nations. In pattern 2 countries the male to female ratio is 1:1 there is a high ratio of paediatric AIDS, probably due to peri- and post -natal transmission. Due to a lack of screening of blood and blood products transmission will still have the potential to occur. National prevalence can exceed 1% and it is estimated that up to 25% of those aged between 15-49 are infected in urban areas. Nowhere else in the world are the numbers of AIDS cases growing as rapidly as in Sub Saharan Africa. In 1991, there were an estimated 200,000 new patients with AIDS. Johnson & De Cock (1994:1523) state that "sub-Saharan Africa accounts for more than two thirds of the estimated cases of AIDS world-wide and over 90% of cases in women and children." The cumulative (projected) figure for HIV infections is estimated at just under four million (Chin & Mann 1990). The United States Census Bureau (1994) estimates that by 2010 the life span in Uganda will have reduced from 59 to 35 years; and the death rate in Thailand will have tripled.

HIV infection was first detected in Thailand in 1985 and in India in 1986 (Weniger, Limpakamjanarat, Ungchusak, et al 1991; Jain, John & Keusch, 1994). By mid-1993 the prevalence of HIV infection in Bangkok had reached 36% in female sex workers, 35% in injecting drug users, and 8% in men attending clinics for sexually transmitted diseases (Brown, Sittirai, Vanichseni, & Thisyakorn, 1994). Similarly high rates have been reported from cities in India, whose population of almost 900 million exceeds that of Africa and South America combined (Jain et al 1994).

Pattern 3: encapsulates countries where HIV has been introduced since the mid-1980s. HIV is found in all of the known risk groups. The cases are mainly amongst foreigners or those in contact with foreigners.

Pattern 4: is in reality a mixture of pattern 1/2, this is where there is extensive spread since the late 1970s, initially the spread was amongst homo-and bi-sexual men and IDUs. Increasing percentage of infection is heterosexually transmitted since the 1980s.

Whilst the descriptions of the epidemic are general, there is overlap between the patterns as the epidemic evolves. For example, in the USA the epidemic appears to be changing into a pattern of heterosexual and IDU transmission equivalent to the pattern of developing nations. It appears that AIDS in many pattern 1 countries is following a path of poverty and deprivation, the heterosexual spread in the ghettos in New York is an example of this trend.

2.4 Infection in Australia.

One of the most baffling characteristics of AIDS is the fact that the disease spread primarily among homosexual and bisexual men and injecting drug users in the industrial westernised societies of Europe, the USA, Australia, and New Zealand, but became a largely heterosexual infection in Africa. There is now rising evidence that HIV is evolving constantly. AIDS researchers in Edinburgh, Scotland, state that

"A substantial AIDS epidemic in heterosexuals will not be obvious until 1995 or possibly not until 2000. There is little doubt that HIV infection is prevalent in heterosexuals in developed countries" (Brettle & Welsey 1991:632).

In Australia, AIDS was first diagnosed in 1982 (NHMRC, 1984). The first cases were among homosexual men living in Sydney, who reported having sexual contact with men in the west coast of America. Robertson and Young (1985) recorded that the first serological evidence of HIV was present in sera collected in 1980 from gay men in Sydney. By 1992 the Australian HIV Surveillance Report demonstrated that there were 3235 cases of AIDS in Australia. That is, these people had developed a disease which meets the Clinical Case Definition for AIDS. Out of this number 2779 (85.9%) were gay or bisexual men and 100

(3.1%) were female. Interestingly, for women the key transmission route had been through the receipt of blood, blood components or tissue. For both men and women the second most prominent factor in the transmission of AIDS was injecting drug use.

HIV testing has been available in Australia since 1985. By 1992, there were 16147 cases of HIV infection. Chapman (1992:132) argues that this reported incidence of HIV "...may be considerably overestimated." Many people tested as HIV antibody-positive appear to get retested, perhaps to verify the result, or in the hope that the virus may have somehow "remitted". However, whilst this may be an overestimation of the numbers of actual diagnoses there are also a number of seropositive people who have not yet been diagnosed. It is notable that the figures reflect the date of diagnosis not the date of infection.

In Australia, 85% of all infections can be attributed to one group - "men who have sex with men" [MWHSSWM] (IGCA, 1993). There is the potential for very substantial growth in the epidemic within this population, considering a 1986 study by Ross, suggested that 11.2% was the proportion of men who had sex with men. This would indicate that up to 750,000 men may have had sex with other men, though not all of these may remain homosexually active. To date, the epidemic has not been uniform in its impact upon the populations of MWHSSWM. It appears that "the gay community of inner Sydney has been severely affected but elsewhere the impact has been less devastating" (IGCA, 1993:18).

As the National HIV/AIDS strategy states, men who have sex with men do not constitute an homogeneous and easily accessed population. While gay identifying men are relatively easy to reach, there are men who for reasons of privacy, identity, and choice who do not readily identify with the gay community. The principal subgroups are:

bisexual men; men who use "beats"; young men; men in rural /remote areas; men of a non-English speaking background; men with disabilities and men with HIV.

Connell, Dowsett, Rodden, Davis, Watson and Baxter (1991) in their study of social class, gay men and AIDS prevention, noted that there is an impact of social class upon the accessibility of what the authors term "unlabelled homosexual activity in the working class milieux" (p.178). It would appear that the social environment of an individual will impact upon their sexual identity and sexual practice. This means that for some men barriers are perceived as being in place which will prevent them readily identifying themselves with the established gay community, which in the main is viewed as "highly educated and affluent, more so than the general population " (Connell et al 1991: 178).

By 1992, 452 cases of HIV were listed as having been heterosexually acquired. Australia is not currently demonstrating the same levels of heterosexual transmission as other pattern 1 countries, such as the UK and the USA. Chapman (1992:137) argues that "...the most obvious answer is that Australian HIV data are seriously invalid in subcategory risk assignment and the likelihood that a significant number of men have denied homosexual contact and/or injecting drug use." Wodak (1990) claims that this limited spread was due to the vigour and speed with which harm reduction policies were instituted and carried out. Karmel (1992) argues that the less rapid spread into the heterosexual population is due to the fact that there has not been the spread amongst the intravenous drug users. This may be, according to Karmel, due to a number of factors: the timing of when HIV was introduced into this group, the patterns of drug use, and the adoption of harm reduction policies, which encourage needle exchange and education. Ross et al (1992) claim that the limited contact with IDUs overseas has meant that there is a low prevalence of HIV in Australian IDUs. The authors went on to say that the majority of infected IDUs in Sydney probably acquired their HIV through sexual contact. There are an estimated 200,000 injecting drug users in Australia (Inter-governmental Committee on AIDS [IGCA], 1993). Only 2% of the AIDS cases reported during 1982-92 are attributed to the IDU category and a further 2.6% to the combined injecting drug use and homosexual / bisexual contact category (IGCA, 1993). Wodak and Crofts (1994:239) note that "the risk of explosive spread of HIV among and from drug users now appears to have abated, but slow diffusion of infection continues."

There are several factors which influence the available data. It is unknown how many injecting drug users have sex with non drug users; the rate of sexual versus parenteral transmission is unknown and the numbers adopting needle exchange are not easy to obtain. Finally, the fact that injecting drug use is an illegal activity will have an impact upon the figures available and the subsequent estimates of transmission.

The rate of HIV infection in Australian sex workers remains relatively low. Studies in Sydney in 1985 by Philpot et al., reported that sex work is not a risk factor except where they also injected drugs (Donovan, B 1990). These figures are perhaps not as reliable as they could be. Men will not always admit having been in contact with a female prostitute. Sex workers comprise a very diverse and often highly mobile population. There is a high turnover of workers, with some people working occasionally and others working on a regular basis. According to the IGCA (1993:31) report .."it would be impossible to obtain an accurate estimation of the total number of sex workers in Australia at any one time. Workers may work in brothels, escort agencies, their own homes or the street . They may be female, male or transsexual." Whilst there may have been no confirmed cases of HIV transmission in Australia from female prostitutes to male clients (Donovan 1990), this may not reflect the reality of the situation. It is recognised that Asian sex workers and drug-dependant sex workers are at risk of infection as a result of their vulnerability (SIREN Project Victoria, personal communication. 1993). In Australia there has been a thriving industry in the area of "sex tours" to Thailand. Koenig (1988) reported that contact with foreign "international " sex workers is a major risk factor for the heterosexual transmission of HIV and Rowbottom (1991) suggested that sex tourism to Southeast Asia will be an important conduit for HIV to enter the Australian heterosexual population. The levels of infection in Thai sex workers as noted by Brown et al (1994) would seem to substantiate this fact.

The impact of the disease on other social groups in Australia has thus far been slight. Crofts (1992) discusses screening in low-risk populations, where it was noted that for all

applicants for life insurance of more than \$250,000, only 14 persons out of the 29,000 tested, were HIV positive. Data gathered since 1989, on persons enlisting in the Australian Defence Forces, found that out of 20,000 persons only one was found to be HIV positive (Chapman,1993). All blood donations since 1985 have been screened. From 1985 to 1990 some 5274981 blood donations were screened and according to Kaldor, Whyte and Archer (1991), only 45 were found to be seropositive. Out of this group, 22 persons did not report any risk factor other than heterosexual contact. The authors of this report were of the opinion that certain individuals may have given false information for fear of the legal consequences. It would appear that the spread of HIV into the heterosexual population remains at a relatively low level. However, this does not imply that the potential for spread is low. That would require all factors to remain constant.

To date there have been data gathered on the transmission of HIV and AIDS and whilst this is essential in the planning process for education programmes, little is known about the impact of the treatment of AIDS/HIV infected persons upon the health and social services. It can be argued that this is due to the fact that the disease is in its infancy and efforts to date have largely centred upon the prevention of further and more rapid spread of the disease.

2.5 Clinical Management.

2:5:1 The Range of HIV Infection.

AIDS is the most severe manifestation of HIV infection. As other presentations of the disease are generally less severe and can last over several years, many of the infections will be dealt with in the primary care setting.

HIV should be viewed as a continuum from the stage of primary infection with HIV to the development of severe life threatening disease. The differing stages of the disease reflect differing levels of viral activity and infected persons are potentially infectious at all stages.

The Centre for Disease Control (CDC) in the USA, developed a classification system, published in 1986, for the clinical stages of HIV infection.

The table, following, describes the CDC clinical classification for HIV infection.

Table 2:2 : CDC Clinical Classification

<u>GROUP 1</u>	PRIMARY INFECTION
<u>GROUP 11</u>	ASYMPTOMATIC INFECTION
<u>GROUP 111</u>	PERSISTANT GENERALISED LYMPHADENOPATHY
<u>GROUP 1V</u>	OTHER DISEASES (SYMPTOMATIC)
SUBGROUP A	CONSTITUTIONAL DISEASE
SUBGROUP B	NEUROLOGICAL DISEASE
SUBGROUP C	SECONDARY INFECTIOUS DISEASE
CATEGORY C 1	SPECIFIC SECONDARY INFECTIOUS DISEASE IN CDC SURVEILLANCE FOR AIDS
CATEGORY C 2	OTHER SPECIFIED SECONDARY INFECTIOUS DISEASE
SUB-GROUP D	SECONDARY CANCERS
SUB-GROUP E	OTHER CONDITIONS

(Source: "CDC classification system for human T-lymphotrophic virus type 111/lymphadenopathy- associated virus infections" MMWR 1986:365).

Tindall and Cooper (1991) report that in 70% of infected persons there is a symptomatic response to the initial viral dissemination (CDC Group 1). The effects range from mild to severe and occur within a few weeks of infection. The clinical signs and symptoms of this stage of infection include: fever, lethargy, headache, malaise, photophobia, sore throat and a truncal rash (Cooper, 1985; Tindall et al 1988). The illness usually lasts for 1-2 weeks and resolves with no residual symptoms. This initial illness reflects the immune response to HIV infection and it is at this stage that antibodies develop in the blood and serve as a marker of HIV infection. Researchers in Sweden, report that: "a glandular-fever -like illness associated with seroconversion to HIV-1 predicts accelerated progression to AIDS and other HIV related diseases" (Lindback et al, 1994:1535). Some people develop lymphadenopathy (PGL), and some develop systemic symptoms for example, night sweats, fever, weight loss, and some uncommon infections. These infections are not associated with death and are classified as AIDS- related complexes (ARC).

In asymptomatic HIV infection there is a low level of viral activity which may last from months to years. In this stage infected persons are usually symptom free (CDC Group II), although they often have persistently swollen lymph nodes (CDC Group III). Testing of blood frequently reveals a mild to moderate drop in the number of CD4 cells. There does not appear to be any difference in prognosis between Group II and Group III infection (Cooper, Tindall & Donovan, 1993).

Symptomatic HIV infection is characterised by increased viral activity. Owing to a decrease in the number of immunocompetent CD4 cells, infected persons become susceptible to a range of minor opportunistic infections and conditions (Cooper, Tindall & Donovan, 1993).

Rutherford et al (1990) reported that more than 50% of persons with HIV infection will develop AIDS within 10 years. This stage of the disease is characterised by major opportunistic infections, profound decrease in the number of CD4 cells and malignancies that cause significant morbidity and mortality (CDC Groups IV-C1 and IV-D).
Diagnosis of HIV infection is made from both clinical observation and the use of laboratory tests, such as the ELISA test (enzyme -linked immunosorbent assay), which involves the detection of HIV specific antibodies in the blood (Cooper, Tindall & Donovan, 1993).
Fahey, Taylor and Detels (1990) report upon several other markers used in the laboratory situation, the most prominent of which is the serum level of free HIV antigen, which reflects viral activity.

Persons who are seropositive are subject to a wide array of opportunistic infections. These infections tend to be multiple, recurrent, and resistant to many of the current therapy regimes. Table 2:3 following is a brief summary of the range of infections which affect seropositive individuals. The table is constructed by body system to enable an overview, but it must be noted that infections are not necessarily exclusive to each system.

Table 2:3: The range of HIV infection

GASTRO-INTESTINAL TRACT	Candida albicans ("thrush"), Staphylococcus; Gingivitis; "lump-in the throat"=follicular hyperplasia; Irritable bowel syndrome; Giardiasis; Amoebiasis; Shigella; Campylobacter infection; non-specific diarrhoea; Herpes Simplex; Cytomegalovirus gastritis; colitis
RESPIRATORY TRACT	Rhinorrhoea; Sinusitis; Auto-immune lung disease; Pneumonia carinii pneumocysti
DERMATOLOGY	Varicella zoster virus (often in the form of shingles); Seborrhoea; Psoriasis; Impetigo; Abscess; Viral warts; Flexural candidiasis; Dermatomycosis; Staphylococcus infections
CENTRAL NERVOUS SYSTEM	Depression; Irritability; Personality changes; Psychosis; Persistent headaches; focal neurological signs; Cytomegalovirus retinitis
LYMPHATIC SYSTEM	AIDS Related Complex (ARC) is a chronic symptomatic illness characterised by swelling of the lymph nodes and immune deficiency Symptoms include:enlarged lymph nodes this is known as Persistent Generalised Lymphadenopathy (PGL); Anaemia; Night sweats;

AIDS is defined by the CDC as the presence of a reliably diagnosed disease, at least moderately indicative of an underlying cellular immune deficiency, in a person with no known cause of immune deficiency nor any other cause of reduced resistance, reported to be associated with that disease (CDC 1983). The main diseases associated with AIDS include

Pneumocystis Carinii Pneumonia (PCP); Karposi's Sarcoma (KS); Cytomeglavirus(CMV); Non -Hodgkin's lymphoma; as well as a wide range of persistent infections. There have been several revisions of the CDC listing to incorporate other conditions as knowledge about the condition increases (CDC,1987, 1991).

2:5:2.Management of HIV Infection.

Persons with HIV disease encounter a range of health-care services at various points during their illness. It can be surmised that the number of services required is in parallel with the symptoms of the disease. The ever increasing number of pharmaceuticals available, which offer prophylactic care for opportunistic infections, will mean that individuals will access medical intervention from an early stage in the disease process. The types of service include inpatient and outpatient services; medical specialists; community services; home support services; for some the use of "alternative" therapies and the support of self help groups and voluntary services.

Mor, Fleishman, Dresser and Piette in 1990 stated that "use of health services, whether inpatient, outpatient, or ER, (Emergency Room) varied as a function of illness severity" (p26). In their study, the authors found that increased symptom intensity was associated with increased outpatient, ER, and hospital use. They concluded that the use of the ER was most sensitive to variations in symptoms. It could be argued that the experiencing of new symptoms motivated people to seek urgent medical attention. The work by Mor et al was carried out in the USA, where patterns of care are different. In Australia, there may be a similar pattern with an increased use of primary health care and/or specialist HIV/AIDS centres at times of symptom change. However, there is no evidence of such a pattern from the literature. Tindall et al.(1992) state that one of the main "challenges for the management of HIV disease is the creation of a continuum of co-ordinated care across the sectors" (p212).

The initial aim of HIV management, for those already infected, is to maintain persons in a symptom - free state for as long as possible and to encourage the individual to be independent of care until required (Tindall et al, 1992). In their discussion of the medical management of HIV, Tindall, Plummer & Donovan (1992) note that individuals who are HIV infected are frequently encouraged to adopt "health-enhancing" practices to maximise their general health status. Following diagnosis of being HIV positive, much time and effort will be spent on the monitoring of general health and the counselling of the individual. In general it is recommended that individuals are monitored every three to six months, at this time the CD4 count will be taken and a full serological count undertaken (Tindall & Cooper, 1991). If an individual is receiving ant-viral therapy, monitoring is recommended every 2-4 weeks, due to the potential toxic and harmful side -effects of these drugs (DeWolf, Lange, & La Voie, 1988; Yarchoan, Perno, Thomas, 1988).

Persons with HIV have the potential to experience a wide range of symptoms. Studies by Klein (1989), and Fischl, Dickinson, and La Voie (1988), have demonstrated the efficacy of prophylactic treatment of opportunistic infections, particularly PCP.

Current medical practice recommends that people with symptomless HIV infection are routinely assessed every three to six months, whilst those with symptomatic HIV infection are evaluated as their condition dictates. As treatments that prolong survival become more readily available, people will live longer with the disease. In addition, as more people become aware of their HIV status, according to Friedland (1990:1000), "the demand for prophylactic treatment will also increase." Most of the drugs used widely in AIDS/HIV treatment to prevent the onset of opportunistic infections fall into the broad classification of "anti-infectives". These include antivirals, antibacterials, antifungals and antiprotozoals.

Until recently, there was little doubt that the anti-retroviral therapies, such as Zidovudine (AZT), substantially increased survival time (Fischl, Richman, & Grieco et al, 1987; Smidht et al.1988). However, recent research findings emerging from the "Concorde" trials (a

three year trial conducted by British and French teams) have brought AZT therapy into dispute. In a letter to *The Lancet* by Albouker and Swart (1993) of the research team, the authors conclude that early treatment with AZT is worthless and CD4 counts are meaningless as a sign of disease progression. The Concorde team states unequivocally that their trial results "do not encourage early use of zidovudine (AZT) in asymptomatic HIV infected individuals" (Press Release, MRC 1993). The Concorde study, along with other studies, including a European -Australian Collaborative Group Trial (Cooper, Gatell, Kroon et al 1993) and the United States Veterans Administration Cooperative Study (Hamilton, Hartigan, Simberkoff et al 1992) reported that this class of drugs has no benefit in extending life in people with AIDS, although they do seem to induce a transient retardation of AIDS symptoms for eighteen months or less.

The other major anti-viral drugs such as dideoxyinosine (ddI) have been shown to have appreciable side effects. The use of ddI has been associated with neurological disorders (Cooley, Kunches, Saunders et al 1990) and pancreatitis, while use of dideoycytidine (ddC) has been associated with peripheral neuropathy (Yarchoan, Perno, Thomas 1988).

The Ninth International Conference on AIDS in Berlin (1993) produced a major increase in information on the current effects of anti-virals and other drug regimes. The journal *Treatment Issues*, following the Ninth International Conference on AIDS stated that " the belief that AIDS could somehow be transformed into a 'chronic and manageable' condition through the right mix of nucleoside treatments was shattered in Berlin" (Link, 1993:1).

The initial focus of healthcare delivery was on acute and terminal care. Progressive improvements in survival rates have caused a change in the pattern of healthcare delivery from acute hospital inpatient to long term outpatient care. This pattern is observable throughout the pattern 1 countries (NSW AIDS Bureau 1990; Hellinger, 1991; Scitovsky, 1988).

International studies have also demonstrated that the acute and chronic care challenges associated with AIDS will continue to grow (Kessler et al 1988; Benjamin, 1989). This is a significant issue in Australia, where the majority of those infected are gay men and issues of providing healthcare to a marginalised group could have particular problems. (This will be discussed in detail in future chapters). The majority of HIV infected individuals are asymptomatic and it still remains unclear how many will develop AIDS; current estimates range from 30-75% (Sisk, 1987; Rutherford et al.1988). Furthermore, it is conceivable that this transition will take many years to occur, especially as the latent period appears to be variable and the latency period continues to lengthen. It is presently estimated to be in the region of 10 years (Taylor et al 1991; Bacchetti & Jewell 1991).

Consequently the scenario of care is changing from acute to long term for those who are HIV infected. Life expectancy will increase as new knowledge and treatments become available and this will result in increased duration of chronic illness associated with AIDS. The increasing life expectancy will also increase the numbers of persons who exhibit neurological and psychiatric impairment associated with HIV. This may mean an increased use of psychiatric services by people in HIV high risk categories (for example, homosexually active men, intravenous drug users), who will present with a variety of psychiatric syndromes (not least, Alzheimer's disease) which are manifest of organic brain dysfunction rather than a functional psychiatric disorder (Price & Forejt, 1986). All of this will mean an increase in the need and demand for chronic care services, coupled with the continued need for acute and terminal care.

2.6 CASE MANAGEMENT.

Chronic care needs of individuals encompass more than their medical status. The functional ability of the person is fundamental to the estimation of the need for care and services. The concept of functional need implies dependence upon others for all manner of personal, social emotional and technical care. The boundaries of care provision extend beyond the

level of medical treatment alone. Functional assessment has long been used in the planning of service provision in care of the elderly, long term psychiatric patients, young chronic sick and the mentally handicapped. Much of what is already known from these areas can be directly applied to the care needs for people with HIV/AIDS.

The concept of a “Continuum of Care” was developed to assist in the management of complex physical, social, medical and economic needs of sub-populations that are demanding users of health and social services. Evashwich and Weiss (1987:16) defined it as:

“An integrated, client orientated system of care composed of both services and integrating mechanisms that guides and tracks clients over time through a comprehensive array of health, mental health and social services spanning all levels of intensity of care.”

This concept is a mechanism through which the needs of the individual are addressed. Continuum of care is fundamental to the concept of case management, through the coordination of a range of services in both the hospital and community setting.

Case management is a three step process that involves :

- development and coordination of a service plan to meet needs;
- assisting in obtaining the services specified in the plan, usually by referral;
- monitoring the individual and altering the plan in relation to the changing needs of the individual over time (Piette, Fleishman, Mor & Thompson, 1992).

The use of case management grew in the 1970s in response to an ever growing demand for elderly care services (Benjamin, 1989). It has been postulated that the use of a case management system would rationalise service provision (Pascal 1989). Case management is in essence the means of coordinating and supplying direct and indirect care services to the client, whilst attempting to ensure a rational service delivery and integration (Mor et al, 1989).

Bayer (1991) comments upon the emerging changes and trends in AIDS management. In the beginning there was a strong bond of co-operation between AIDS organisations (predominated by gay men) and public health authorities. This linkage enabled the development of projects such as the "Shanti Project" and others such as the demonstration site set up in the mid 1980s, in San Francisco, by the Robert Wood Johnson Foundation to develop community based HIV/AIDS care, based upon the concept of case management. From this work a series of models were developed as follows:

1. The hospital discharge model.
2. The "traditional" model of case management. This incorporates monitoring and coordination of the client's needs throughout, from diagnosis to the terminal stages of the disease.
3. The direct care model.
4. The purchasing of additional services in addition to performing the traditional role of case management (Piette et al 1992).

In the first decade of AIDS in Western societies Bayer (1991) notes that an alliance of gay leaders, civil libertarians, physicians and public health officials began to shape policies for dealing with AIDS. The thrust of this policy shaping alliance was to make AIDS an "exception " to the previously used public health measures of quarantine and notification. Bayer (1991) notes that in the early years of the AIDS epidemic Western Government officials had no option but to negotiate AIDS policy (and service provision) with representatives of well organised gay communities and their allies in the medical and political establishments. The case management system was seen as the way to deliver care and control costs. In NSW the first three models have been employed. The "traditional" and the discharge models have been utilised in areas of high prevalence, such as Inner Eastern Sydney (NSW AIDS Bureau, 1990).

In essence, the models are similar and all are concerned with the provision of direct care services. Differences between the models relate to the point in the care continuum when intervention occurs and who is the case manager. For example, in the traditional model, in the main, it is a medical practitioner who would be the case manager and the point of contact is from diagnosis through to death. The discharge model is utilised at the point of being discharged from a direct care facility, the discharge planner could be any designated health professional. The key issue surrounding case management is not so much the approach taken, but rather the recognition that there is a need for care to be coordinated and organised, on behalf of and with, the individual who requires assistance. When there is no mechanism to coordinate care the individual is vulnerable to being exposed to the following:

- multiple care provision, by a variety of professionals, who all independently organise a service for the patient;
- no care provision as no-one took charge.

For the service providers, lack of care management could result in duplication of services which is resource intensive and costly.

Fleishman et al (1991) in their discussion of AIDS case management from the client's perspective, noted that clients had deeply held concerns about the amount and levels of information available to a wide range of health professionals. The authors expressed the view that this factor inhibited the effective use of case management for this group of individuals. However, case management for individuals with AIDS, was successful when there was the ability to coordinate care from one site. This was demonstrated by the use of a collaborative case management programme, in which the hospital was the focal point in a district for all services (hospital and community) being provided to people with HIV/AIDS (Vautier & Carey 1994). In a similar vein, Myers et al .(1994) discussed the relevance of designing services based on the provision of community services. The authors found that in an urban environment where there were a number of care options available, consistency in the level and type of community services available, reduced the duplication of service use. Piette et al. (1990) in their comparison of hospital and community case management

programmes for people with AIDS noted that communication between health professionals was a key to successful case management, but trust in health professionals was crucial to the success of any programme. The authors noted that there were several key factors which influenced the ability to manage care as follows:

- health care professionals who were seen by clients as being empathic;
- communication between hospital and community sites;
- the presence of a visible gay community enhanced the ability to inform those seeking care, where care was provided;
- the use of education programmes for health professionals in the area to inform them of care options available;
- the discipline (background) of the case manager (Twyman & Libbus, 1994; Jenkins & Sullivan-Marx, 1994).

It does appear from the literature that, even in the light of inhibiting factors, case management is effective in reducing costs of care provision for people with AIDS (Contra Cost, County 1991; Twyman & Libbus, 1994). It widens the range of appropriate, available care provision (Taylor 1994) from solely the hospital site into the community and in particular rural areas (Bergen 1994). However, Krauthammer (1990) noted that divisions have begun to appear in the alliance of gay organisations and the medical and political establishments, influenced by the rising costs of care and the realisation that the initial estimates of the levels of infection were too high. Krauthammer (1990) discuss the notion that this will in turn affect the level of commitment to case management programmes and other means of services provision such as needle exchange. The adoption of case management in NSW can only be viewed as a positive step. However, how effective the system has been in coordinating care provision is currently unknown. Indeed it is unknown how far the system of case management has been adopted by health professionals in NSW and in Sydney in particular. It is envisaged that this study will in some part reveal the use of case management for individuals with HIV/AIDS.

2:7 Conclusion.

This chapter has attempted to give an overview of the biological, epidemiological and clinical management of HIV/AIDS. The purpose of the chapter was to give the necessary background which has relevance to the subsequent treatment of HIV/AIDS, the medical management and the identification of the groups most affected by the disease. The controversy in relation to the nature of the virus and its treatment is fundamental as it serves to illustrate that HIV/AIDS is a constantly evolving phenomenon which is the source of much debate.

HIV/AIDS is a new disease and one for which there is no known cure or vaccine. The clinical syndrome may occur many years (on average 8-10 years) after infection and this makes clinical management of the disease difficult due to the unpredictability of the disease. There appear to be four clinical phases of the disease:

Seroconversion illness from first contact with the virus. This is a wide variety of symptoms which may require attendance at a doctor. For instance it may present as a "flu-like" illness with a widespread rash. This period may take six to ten weeks.

During the symptom free period the person may present with mild symptoms such as diverse pain, or Bell's Palsy. At this stage the CD4 lymphocyte count would be between the normal level of 500 to 1000.

The depletion of the immune system is when minor infections start to occur with alarming regularity, for example, gingivitis, oral thrush and fungal infections such as tinea. During this phase the CD4 count drops to around 200.

AIDS defining diseases are characterised by severe opportunistic infections and cancers, such as Kaposi's sarcoma and PCP. A drop in the level of CD4 cells below 200 is now viewed as being an AIDS defining stage.

Transmission of the virus is reliant upon the correct conditions. HIV is a difficult virus to transmit, it requires the exchange of bodily fluids and its most efficient route is via blood transfusion. The pattern of HIV transmission is a social pattern. In some countries, the pattern is predominantly heterosexual; in some such as Australia, predominantly homosexual; in some for example Italy, it is associated with injecting drug use; in others such as Eastern Europe it has been medically acquired through the re-use of injecting equipment (Ross,1994).

Treatment of the disease is ever changing in the light of medical and scientific discoveries and focuses largely upon the prevention of opportunistic infections. There is much debate in the scientific literature about the efficacy of some of the new drugs which are currently being used. Much of the debate centres upon AZT and its effectiveness. The medical management of the disease appears to be conducted in an ever changing environment as new information becomes available. It is recognised that there is a need for a structured method, such as a case management approach, to be taken in order to effectively provide services to those who are affected.

HIV/AIDS has wide reaching social implications and any form of policy making in the area of health services will require to take cognisance of the social factors which affect care provision. It is noted that any form of structure requires policies to enable and control actions, and chapter three describes some of the concepts surrounding AIDS policy development. This chapter has supplied background information in terms of the biological, epidemiological and medical management of HIV/AIDS. The chapter following describes the social factors which impinge and impact upon the delivery, design and provision of health care services.

Chapter 3 : Social perceptions of AIDS and the subsequent impact on policy development.

Overview.

This chapter discusses the impact of the AIDS epidemic on policy formation and the application of that policy at federal and state levels. Although this is not the main focus of this thesis it is essential background as it places the AIDS epidemic in its social context. Foucault (1973) in his book *Birth of the Clinic* argues for there being a typical disease of the age: one which reflects central preoccupations with the social order and the place of the body within it. AIDS is seen as being reflective of the social mores of the late twentieth century but it is a disease which has had an impact upon the views of sexual freedom. It is argued that the key difference between AIDS and other epidemics of the past, is the link with sexuality. This chapter outlines why this difference is important, primarily as it affects the accessibility and provision of services. As Ross (1994:325) comments: " the point must be made very clear that the very epidemiology of AIDS is based on historical social and anthropological factors and will continue to be." AIDS care does not take place in a vacuum, this chapter describes the social factors which have and will continue to affect the environment in which care takes place and illustrates how perceptions of the epidemic have affected the choices made about care provision. It is argued that the labeling of the disease and its subsequent categorisation has been linked to how policy has developed. For example, the notion of plague was revealed in the policies of containment, in terms of health service response.

Initially, AIDS was viewed as the **plague of the twentieth century**, the notion of medical control and progress being thrown into disarray. AIDS tapped into the most fundamental of public health concerns, the control of infectious, deadly disease. There was a sense of urgency and crisis. The notion of plague was revealed in the policies of

containment. There was a growth in the number of statistics held by various organizations, and the emergence of new agencies.

After a period of time it became apparent that people were surviving with the disease. AIDS became labelled as a **chronic disease**. There was a shift from control of a catastrophic illness to the management of a chronic disease. There was the removal of the sense of urgency that enabled the generation of funding. Policy developed in the areas of screening and treatment. This gave credence to the view that prevention was the responsibility of the individual, and the idea of AIDS as a "lifestyle" disease was reinforced. To view AIDS as solely a chronic disease is inappropriate. It reduces the impact of AIDS as an infectious, transmissible disease.

AIDS is an infectious disease, which is chronic in terms of longevity and has a global impact. Therefore, **AIDS is a chronic, infectious pandemic, which has a global impact**. This stage of the disease perception is one that encapsulates both the infectious and chronic aspects. This implies a need for both urgent and widespread actions in terms of prevention, plus, the development of long term strategies for disease management and provision of social support mechanisms.

The **response of the health care services** in three pattern 1 countries, the USA, UK and Australia demonstrate a pattern of "bottom up" approaches and consensual management with varying levels of community involvement. In Australia, the approach was one of consensus management.

The practical application of the **current service response in Australia** has centred upon areas such as: national education programmes, specific programmes, for example, needle exchange and the development of centres specific to AIDS care.

The **Federal response** has centred around funding through the matched funding programme and the support of the Australian Federation of AIDS organizations. AIDS policy has been formulated through the consensus approach. This has been a route fraught with difficulty, as the different interest groups have vied for position. The most recent Federal policy development reflects a shift in emphasis towards "normalization." This change reflects the government's attempt to specify choices in a rational way and place them in the arena of the cost-benefit approach.

The **health service response in New South Wales** has centred upon a multi-stage approach, with centres of clinical excellence and information being located in Sydney, at the epicentre of the epidemic. Out of the Sydney area, services have centred around the Sexual Health centres which have received funding, through the matched funding programme. There has also been the development of state-wide prevention programmes such as needle exchange. Databases, such as the HIV infection database at the Albion Street clinic, are also initiatives that have been undertaken at state level through the matched funding project.

3.1 The Perceptions of AIDS and the resultant impact on Health Services.

Throughout the developed world there has formed over time a set of responses to epidemics. These responses have been increasingly effective in controlling infectious disease (Dowling, 1977). At the beginning of the AIDS epidemic there seemed no need to doubt that the problems posed by this new infection could be solved promptly and efficiently by applying the well-tested methods of surveillance, research, prevention, and treatment in a coordinated effort, involving already established health care resources. However, AIDS is not simply a medical problem. Rosenberg (1988) discusses how for the past two decades in America there has been public discussion about the appropriate response to the control of disease. From these discussions he asserts that the social construction of disease, its cultural meanings and the power of the medical profession to name and manage social ills have been brought to the fore in the light of AIDS.

In the 1970s public health officials in developed societies realised that the political role in future health crises would be less about dismembering the water pump -- Dr. John Snow's decisive action in curbing London's cholera epidemic - than teaching people how to avoid the infectious source in the first place. Preventive education is a fundamental part of the health care system and one that is of equal importance as clinical management in the AIDS epidemic.

Rosenberg (1988:13) asserts that "no single event has had a more dramatic and illuminating impact than AIDS. It has proved an occasion for labelling, but it is not simply an exercise in labelling." The labels and the meanings attached to the AIDS epidemic in many ways have served to shape policy and at the same time have been reflective of the views of society. AIDS, asserts Rosenberg (1988:14) "has, in fact, helped create a new consensus in regard to disease, one that finds a place for both the biological and social factors and emphasizes

their interaction." It seems relevant to describe some of the ideas and associated perceptions that have been the defining factors in the construction of AIDS policy.

Throughout this discourse the themes of racism, homophobia and heterosexism are implied. It is beyond the scope of this thesis to deal adequately with these subjects, but their impact cannot be underrated. Aggleton (1988:12) stated that "these divisive structures have played a critical role, in establishing moral and political agendas." No study on AIDS can be addressed without acknowledging the importance and role of issues such as homophobia, which in many ways has served to shape the actions of individuals.

Oppenheimer in 1988, stated that

"the history of AIDS was not simply a series of chronological events. Rather it was a history that was necessarily constructed and consequently could not be simply inferred from the biological properties of HIV or the pathological properties of the disease"(p267). It is argued that the resultant development of policy is also not chronologically defined, but has been reactive to the consensus of popular opinion and political structures of the period.

Sontag (1988) in her book "AIDS and Its Metaphors" commented that AIDS was the first major disease to be known by an acronym. Perhaps this reflects the inability of society to grasp the enormity and subsequent implications of a complex disease. It might also reflect the fact that there were no previous events that adequately matched and symbolized the pattern shown by AIDS. Other diseases, in particular cancer, were symbolized and discussed, albeit in euphemisms ("the big C") but AIDS had not yet developed any degree of symbolism. AIDS has forced people to come to terms with a new and often terrifying series of events, healthy young men dying in their most productive years, the intermingling of the taboos of sex and death. Thus, the social meaning attributed to the bodily experiences of illness and death has intimately touched upon the ideals (and ideas) held about sex and divisions in society. AIDS has also served to raise the profile of concepts such as social

responsibility, individual privacy, social order and stability. In doing so, it also highlighted the reactive nature of policy formation, reflecting the perception of AIDS at a particular time.

Fee and Kreiger (1993) have argued that there are three distinct phases of AIDS, each having different implications for health and social policy. Initially, AIDS was seen as a plague embodying all the concepts of sudden catastrophic epidemics of the past. As time progressed and the disease did not have the predicted devastating effects -- people were surviving -- AIDS became normalized as a chronic disease, similar in ways to diseases such as cancer. The third phase is reflective of the current state of knowledge of the disease; a slow moving, long lasting pandemic; a chronic infectious ailment manifested through a myriad of specific HIV- related diseases. These three phases will be used as the outline to describe how the AIDS epidemic has been identified, animated, legitimated and demonstrated in the last twelve years and how structures and policies have emerged.

3.2 : The Plague of the Twentieth Century ?

In the book *The Mirage Of Health*, DuBos (1959) commented:

"In Europe, leprosy was prevalent in the fourteenth century, plague in the fifteenth, smallpox in the seventeenth and eighteenth centuries, scarlet fever, measles and tuberculosis in the twentieth century. No one was prepared for the fury of the influenza epidemic when it struck after World War 1. Who can say what is in store for the future and how effective modern methods of prophylaxis and treatment, the vaccines and drugs, would have proved in the face of these killing epidemics to which Western man had not developed any natural resistance at the time they reached him" (p.190).

These words were to prove prophetic in the light of AIDS. Plummer (1988:31) stated that "AIDS has become *the* disease of the twentieth century". The World Health Organization announced in the mid 1980s that AIDS was (and continues to be) its major priority and an enormous industry, encapsulating the media, medicine and the general population, has been

built up around the syndrome. Western Governments have established specific committees and mechanisms to deal with the disease and its effects. In Australia, at Federal level, the National AIDS Task Force and the National Advisory Committee on AIDS were established. These bodies were later to evolve into the Australian National Council on AIDS.

On the surface it would seem that the formation of august bodies to deal with the epidemic was sparked by panic. The realization arose that in the latter half of the twentieth century there was a disease process that was capable of destroying people in the developed nations. It had been widely supposed that modern medicine was firmly in control and that science would conquer and control all in its path.

There is little doubt that AIDS has caused concern for a number of reasons. First the overall global impact and the projections of what Sontag (1988) calls the "future ill." That is, those people who are infected but do not yet exhibit symptoms of the disease, present a gloomy picture. Second, the disease or rather the myriad of diseases which comprise the AIDS syndrome, all add up to a wide spectrum of agonizing and debilitating diseases that are ultimately fatal. The fact that, initially, AIDS was seen to affect specific groups in the community, specifically young men in their productive years, was enough to fuel the interest of the scientific, medical and political communities.

The initial phase of AIDS was first identified through the observation of a series of strange events affecting a previously healthy spectrum of society, that is, gay men. It is not the intention to chronologically describe the events that led up to the naming of the disease, suffice to say that initially it was known as "GRID"-- (Gay Related Immuno- deficiency Syndrome) -- "a name which was considered prejudicial by gay activists" (Patton C 1990:59). The popular media described the disease as the "gay plague" and the concept of a "plague of others" was conceived. In being identified as such, three social myths were brought to the fore:

1. Homosexuality is a social, medical and political problem with the old association of Gay = Ill

2 Mass infectious diseases = problem of under-developed countries.

3. Disease is a prominent and feature of the ghetto. For the gay population the ghetto is not necessarily geographically defined; for the poor the converse is true.

Prior to AIDS there was thought to have been worldwide eradication of infectious disease, (or at least it was no longer a problem of developed countries). Humans were in control and were no longer to be subjected to the tyranny of infectious disease. AIDS was to challenge this view. Here was an unknown virus, one whose route of transmission was to impinge upon that most valued concept of western society --privacy. AIDS also confronted the idea that the division of disease was representative of societal divisions. In the West there were chronic diseases associated with aging populations, whilst serious infection was a product of less developed countries.

AIDS in the developed nations of Australia, Western Europe and North America was seen as a disease of unknown origin, a silent fatal infection that killed young gay men who were in the prime of life. This was a disease of hedonism, wealth and deviant sexual behaviour (Sontag 1988). On the other hand, AIDS in Africa was a disease of poverty and heterosexuals, just another facet in the tragedy that is Sub-Saharan Africa. Interestingly enough Africa was to be seen as the source. Why did no-one deem it to be the other way around?

AIDS was perceived as an illness of sexual excess and perversity. This concept was to carry over into the heterosexual spread of the disease in Sub-Saharan Africa, the studies on prostitution in East Africa, reinforced the idea that the spread of the disease was due to sexual promiscuity (Patton 1990).

This was a time of blame, nations in the beginning of the epidemic blamed each other for a disease none wanted to claim.

The concept that plague comes from elsewhere was fundamental and AIDS was perceived as a disease that is contracted from “dangerous others.” These ideas are not new. In medieval times the Jews were blamed for the spread of bubonic plague, a minority group on the fringes of mainstream society; the same principle applies to AIDS. In Dostoevsky’s novel, *Crime and Punishment*, the character Raskolnikov dreams of plague--” a terrible new strange plague that had come to Europe from the depths of Asia.” Fourteen years after the start of the AIDS epidemic the true origin is still unclear, and is perhaps less important as a reference point than the effects of the disease upon social and health policies. One of the most striking examples of containment of “dirty foreigners” was the practice of barring persons who were HIV positive from entering the country, a practice that was attempted in the USA and Australia. It was declared unconstitutional in the United States, following the imprisonment in April 1989 of a Dutch AIDS educator, who was jailed for refusing to return to the Netherlands when he was prohibited from entering the US due to his HIV positive state (Altman & Orkin 1990). In Australia, all persons who are applying to enter the country for an extended period must undergo an AIDS test (Migration Health Regulations, Australia, 1990).

As numbers grew, AIDS became likened to the great tides of infectious disease that ravaged Europe till the end of the 1920s, with the analogy of the Black Death being used both in the popular media and by association by health education campaigners. The best example of this being the “Grim Reaper” campaign (1987) waged on a national scale in Australia. The “Grim Reaper” is found throughout medieval writings and was a favoured representation of plague. It bore the association of evil. The plague was thought to be a form of divine retribution for past deeds. It can be argued that using the representation of the “Grim Reaper” fostered the idea of a tainted community being judged and indirectly served to feed

the prejudices supported by certain factions of the community, primarily conservative social commentators. Illingworth (1991) in her critique of health education methods for AIDS noted that the Grim Reaper campaign was the best example of a "manipulative quick fix" approach, a prime example of reactivity on a policy level. Watney (1989) identified two approaches in health education that were reflective of the perceptions of AIDS. One is the "Terrorist Model" where HIV is viewed as "an illegal immigrant, an external invader, a dangerous alien subversive." The other is the "Missionary Model" where HIV is viewed as a "heathen entity, strange and exotic- thriving on immorality, bestiality, unnatural acts and ungodly practices, of which it is also seen as the product"(Watney 1989:20). AIDS was a problem of deviance. This disease was the ultimate revenge on a liberal society.

This initial phase was a time of revival for medical historians and epidemiologists, as people demanded to know whether past epidemics could yield clues on how to deal with this new challenging epidemic. Crimp (1988) surmised that the contemporary meaning of plague (as a disease which was able to impact upon the lives of people in the affluent west and over which they had little control) was made relevant in the face of AIDS. This was a time when fear and ignorance surrounded the disease, the surfacing of unreasoning prejudices, social discrimination against gay men and intravenous drug users. There was a sense of emergency and of trying to contain the disease. Sadly, some persons thought that this would be best achieved by quarantine and isolation that can only be viewed as Draconian methods of control. Some others made a case for the generation of funding and there was an increase in gay activism. It was also a time for the breaking down of the taboos about talking about sex and sexuality, on an individual and community level and in the mass media.

At the beginning, AIDS tapped into the most fundamental of public health concerns, the control of infectious deadly disease. Epidemiologists were fascinated with the "exotic" life style of gay men which included drugs (poppers) and large numbers of sexual partners. Miller (1991) summed up the initial approach thus...

"The medical gaze has become a voyeuristic stare fixing its sorry victims in a parodic tableau of deviant sexuality" (p56).

Epidemiologists emerged as "disease detectives" seeking cause and noting effect, searching for the origin of AIDS (Patton, 1990). The result was descriptions of the sexual behaviour of gay men in particular their preference for particular forms of sexual expression and the labeling of their behaviour in negative terms, such as promiscuity. This "fast lane" lifestyle and its description was to nurture the belief that AIDS was a natural consequence of promiscuity and the lifestyle of gay men. The categories of people at risk as defined by epidemiologists and others has also served to fuel the belief that AIDS is a disease of "others".

AIDS as plague put at risk the common belief in medical progress, yet the history of epidemics has taught us that medicine has had little to do with the halting or control of infectious disease. Rather, nutritional and environmental changes have had the greatest impact. McKeown (1979:12), in his book *The Role of Medicine*, suggested that : "medical intervention has made, and can be expected to make, a relatively small contribution to the prevention of sickness and death."

Friedson (1970) in his book *"Profession of Medicine"* discussed how the acquisition of specialist knowledge by medical practitioners contributed to the growth of professional (medical) dominance which excludes all other practices. It could be argued that AIDS has further contributed to professional dominance as medical personnel acquire further knowledge about the disease. Rosenberg (1988:17) notes that:

"Definitions of disease have come to play a particularly prominent role at the margins of medical competence where the authority of medical practitioners and medical ideas is most obviously subject to negotiation."

This can be seen as particularly relevant to AIDS. After all, plague is a problem over which medical practice has the potential to exert control. However, the dominance of the disease

entity approach has left the medical profession ill-prepared to address other inter-related problems that are not directly part of this approach. For example, it is appropriate for an immunologist to study AIDS but there may not be automatic agreement on the policy implications of their findings. The medical profession, for a variety of reasons, has been placed in a position by society, whereby they have had to play a gate keeping role as well as a therapeutic one. This perhaps arose out of the success of medicine itself. An example of this is the helping to banish the randomness of acute infectious illness, through the programme of childhood immunization. However, as Rosenberg (1988) notes this was at the cost to society of "granting enormous social power to medical practitioners and institutions" (p25).

In Australia, Misztal (1993) noted that at the beginning of the epidemic there had been a relocation of medical politics outside the established corridors of power. In 1988-89, the medical profession severely criticised the Federal Government's management of the AIDS problem, on the grounds that there had been insufficient emphasis on public health measures (Mitzal, 1993). Although there were political disagreements between the medical community and governments this did not prevent a number of medical research projects being funded in Australia and throughout the developed world. Indeed Plummer (1988), somewhat cynically, commented that the road to the Nobel prize is paved with AIDS research. Linked with the growth in medical research comes the generation of exploitative markets and Industrial Medical Empires (Navarro, 1976), through the upsurge in new drugs and therapies to deal with AIDS.

Those most affected by the "plague" have not been passive consumers. Indeed it can be argued that the gay community has found career opportunities through the auspices of organizations, such as ACON (AIDS Council of New South Wales). This comment could appear cynical. However it is not intended to undermine the valiant efforts of community care, education, and support under taken by ACON and similar organizations. Patton (1990), in her book "Reviewing AIDS", describes the "AIDS services industry" and the

blurring of boundaries of the roles of the key players. The roles of "expert, volunteer and victim" are inter-related and as such are difficult to extricate from one another. Patton discusses the evolution of the "AIDS service industry (ASI)" in the USA. She notes that this industry arose from the "grass-roots" of the gay movement and encompassed the concepts of self-help and community empowerment. Patton clearly describes the increasing bureaucracy and institutionalisation of the ASIs as they became larger. In Australia, the pattern of ASI development could be seen to be very similar to the USA. HIV primarily affected homosexual and bisexual men, "who formed an organised community with many well-educated; articulate and influential members who were prepared to respond quickly" (Wodak & Crofts 1994:239).

AIDS as plague is revealed in the subsequent policies that arose in the early days. They include immigration as previously discussed, but more insidious is the collection of statistics, and the emergence of many new agencies that hold databases on those infected. These could be viewed as part of what Foucault (1978) described as the "exclusion" of some people whilst "including" others under whole new systems of social control (p198-9). It could be argued that the formation of "gay ghettos" in many major cities (for example, the Castro in San Francisco, Darlinghurst in Sydney) has been both positive, in the sense of forming an identifiable community group with a political profile, and negative in the sense of being an identifiable ghetto which is in some aspects separated from the rest of the community.

It must be remembered that, until very recently, homosexuality was regarded by the medical profession as a sexual deviance. However, the formation of "gay ghettos" and the subsequent levels of political activism, in effect closed off the "medical gaze" (Foucault, 1978) and in some ways shifted the gaze from a medical standpoint, through to a social view, where the concept of lifestyle choices dominated.

In reviewing AIDS as “plague” it is hard to ignore the worldwide media coverage that has done much to stimulate the fears, attitudes and opinions of the public, through what can only be described as a massive and stigmatizing campaign. AIDS in its most sensationalist form sells newspapers and air time (Vass 1986). In his book, “Covering the Plague” Kinsella (1989) details the reporting of AIDS by the media in the US as a means of chronologically describing the AIDS epidemic. Kinsella acknowledges that far from being objective, journalists have treated the news of AIDS by including their own prejudices and biases. Lupton (1994:4), states that:

“From the time that the symptoms of AIDS were first recorded, in the absence of other sources of easily accessible information, the news media have defined AIDS for the developed world, set the agenda for public discussion of AIDS issues, and influenced key decisions for policy makers.”

Thus the questions being asked are reflective not of AIDS, but of the nexus of societal meaning and metaphors.

AIDS as plague fitted into the sense of world catastrophe and for some AIDS was seen as the holocaust of the late twentieth century. This was best reflected in the writings of Larry Kramer, playwright and gay activist. His play “The Normal Heart” clearly illustrated this. The concept of holocaust did serve to create a sense of extreme urgency and perceiving AIDS as a devastating plague was useful in mobilizing people from all avenues of life to act. Funds were generated, research commenced and action was taken.

Finally, as the sexual and blood borne routes of transmission make AIDS a relatively difficult disease to transmit, at the end AIDS cannot be considered as a plague, as the transmission does not fit the plague model; plague spreads easily, AIDS does not.

3.3: AIDS as a Chronic Disease.

AIDS does not kill people quickly. It became progressively more apparent that there was a chance of long term survival. This was best illustrated in one of Armistead Maupin's books, which chronicle through fiction, the impact of AIDS in San Francisco. Michael Tolliver, the central character, who is HIV positive says:

“Most people thought you got this thing and died, truth is you got this thing and waited”.

This comment serves as an adequate introduction. There is the move from AIDS being viewed as an instant, urgent plague, to being perceived as having the potential to be controlled.

The progression from plague to "social phenomenon" occurred, according to Herzlich and Pierret (1989:1237), "{w}hen AIDS became more than a serious illness: it became a public issue." The authors went on to note that AIDS was no longer a problem of individuals alone, but was now a problem for government. Herzlich and Pierret assert that AIDS had now reached fruition as a social phenomenon; it was no longer presented as mysterious or novel.

Cancer, coronary artery disease and diabetes are all diseases having some form of treatment, (invasive or palliative) which enables the sufferer to live for a period of time following diagnosis. In each of these diseases "lifestyle" factors play a significant role. AIDS, too, has become progressively individualised as a disease of lifestyle. Coupled with this is the evolving range of prophylactic drugs and therapies that have enabled the prolongation of life. AIDS has become a disease that can be managed and as such has been normalized into a chronic disease.

However, despite this normalization into a chronic disease, AIDS remains a disease of "others" Both media and policy consider separately those who acquired AIDS by non sexual means who are classified as having "medically acquired AIDS." Since there are "innocent victims" (Lupton 1994), therefore there must be "guilty victims," and this has led

to the condemnation of the “guilty“. Sontag (1988) clearly argued that AIDS was not a mysterious affliction, striking randomly. In Western society, most people knew how they got it.

There is a very clear distinction appearing between AIDS and the other chronic diseases. Cancer and coronary heart disease can be viewed as a weakness of will over lifestyle, but, for AIDS, there was the perception that lifestyle dominated will.

In viewing AIDS as a chronic disease there is the crucial shift in emphasis. Treatment (and the search for a cure) is the province of medical science. The balance of power from AIDS activists and epidemiologists was to shift back to the areas of clinical and researched based medicine. Globally this change was best noted in the late 1980s, and was epitomised by the regulation of drugs. The issue concerning freedom of access to experimental drugs was to be a crucial item at the Fifth International Conference on AIDS in Montreal 1989. The Montreal Conference saw the need for police protection for some of the speakers as they were jostled and harangued by AIDS activists who saw the regulation of experimental drugs as impinging upon their “right to choose.” The Montreal Conference was the arena for the confrontation of political activism versus medical science. This was to prove to be a notable event in the shifting of the balance of power and control in the treatment and conception of AIDS. Politically AIDS had become an issue of civil rights. Scientifically it was an issue of management and medical control.

There are according to Dixon (1991)

“At least three overlapping categories of public health interests associated with the regulation of drugs: the protection of people, the conservation of health care resources and the maintenance of the ability to do science” (p 125).

In Australia, the protection of people was to surface in the form of protection of health workers. There was a call from the medical profession to screen patients, in order to protect

doctors and other health workers from AIDS. Misztal (1993) noted that the 1989 AIDS summit was an indication of the view held by many doctors, that the Federal government :

“had placed too much emphasis on the civil rights of AIDS patients and high risk groups and not enough on traditional types of public health measures, especially routine testing for HIV”(p87).

This view directly coincides with Dixon's view which is that the greater good outweighs the needs (and rights) of the individual .

In viewing AIDS as a chronic disease there is the shift from control to management.

Coupled with this is the removal of the sense of urgency that enables the generation of funding. In medical economics, the cheapest patient to treat is the one who is very quickly dead, the next being the person who is quickly cured. In the regulation of drugs for AIDS this was to be a powerful argument; the sacrifice of the autonomy of the individual (whereby an individual felt that they had the right to choose their treatment options, fostering the notion of "I'm infected with a fatal disease therefore I have nothing to lose by trialing these untested drugs") was in the public interest, because safer, more effective and more economical treatments could be developed for future patients. In this regard the argument directly parallels that for the health care costs and treatments for cancer.

In the 1980s, as the level of knowledge and expertise surrounding AIDS grew, the disease mechanisms rather than the origins became paramount. The clamour to develop policy that was concerned with screening and treatment gives credence to the view that prevention was the responsibility of the individual. Thus, the concept of AIDS as a “lifestyle“ disease is reinforced. However, the individualistic approach that is epitomised in the chronic disease model has not reduced the incidence of non communicable chronic diseases.

Finally, to view AIDS as a chronic disease is inappropriate. It ignores the fact that AIDS is an infectious, transmissible disease and as such does not comply with the classic chronic disease model.

3.4 : AIDS as a Chronic Infectious Pandemic.

AIDS cannot be equated to the classic chronic disease model. It remains an infectious disease, even though the route of transmission makes it a difficult disease to contract. AIDS has had a global impact and as such is pandemic.

This phase is reflective of the current state of knowledge of the disease, that is, it is a slow moving, long lasting pandemic; a chronic infectious ailment manifested through many types of specific HIV- related diseases. It must be remembered that strictly speaking AIDS is not a disease, rather the name is an umbrella term under which a spectrum of illnesses are placed. The definition of AIDS requires the presence of other illnesses.

The use of language is not just semantic, rather it is reflective of the nature of the disease and reflects the fact that AIDS is much more than the clinical management of symptoms. By emphasising its infectious nature, the need for screening, prevention and education are brought to the fore. As argued by Fee and Krieger (1992), the different time frames for infectious and chronic disease have different implications for disease prevention policies. The plague model fostered a general attitude of crisis; the chronic disease model expanded the time frame, but emphasised the clinical management of the disease. If AIDS is viewed as a condition that encapsulates both infectious and chronic aspects, there is a need for both urgent and widespread actions in terms of prevention. Long term strategies for the management of the disease, and provision of social support mechanisms for those who have already tested positive, must be developed.

In taking this approach it is essential that the failures of prevention are recognized. For example, the re-emergence of tuberculosis has demonstrated that the pharmaceutical solution is one of respite, and unless the pre-existing social conditions are addressed the disease has the potential to re-establish itself. There is the requirement for a consensus policy that

addresses both social and health care issues. For example, for people with AIDS, there is the need for social change in the legal system that would, as argued by Weeks (1985), affect the historical patterns of discrimination and the cultural patterns of sexual anonymity. People fear disclosing that they are gay, for fear of discrimination and prejudice and consequently remain anonymous. Same gender sexual activity has long been a social taboo and has engendered a culture of anonymity. A long term strategy for the prevention of sexually transmitted disease, must include the effective implementation of anti-discrimination statutes, in the areas of employment, sexual vilification and provision of services.

The fact that AIDS is a chronic as well as a communicable disease requires as stated by Fox (1988:321), "the reform of the health care system to meet the challenge of treatment and management of all chronic ills." Resources in the west are becoming increasingly limited and it seems that there is a need for a rational system of financing medical care; if this were properly addressed it would not only mean a better ability cope with HIV related diseases, but would provide a framework for dealing with other chronic disease.

The current reporting of AIDS statistics incorporates the epidemiological categories of risk. This masks the social class differentiation of health issues. Official health statistics report cases by age, sexual orientation, gender, mode of transmission and ethnicity /race. There is no mention of poverty or social class. The invisibility of class in the official data mirrors the invisibility of class in public policy. Class is increasingly important as it becomes apparent that the pattern of the disease is changing, particularly in the United States. Kreuger et al (1990) have reported that, when all other factors are controlled for, it is those on the lowest income bracket in the US who are most likely to be seropositive. In the past people with AIDS came from all strata of society, however the work by Krueger et al (1990) suggests that in the future it is those in the lower income brackets who will be most affected.

The movement away from plague with its emergency response and from chronic with its static, individualistic “risk groups” requires a widening of the policy formation, away from the biomedical individualistic approach to a consensus approach. The consensual approach deals not solely with the physiological aspects of the disease process, it acknowledges that illness is more than the domain of the medical and allied professions. This approach also acknowledges that there is also a valuable contribution to be made by others, for example, people with the disease and their carers. According to Myszal (1993), this was the approach taken in Australia. It included all interested parties and, given the level of containment of AIDS could be viewed as a success. Interestingly, due to a myriad of reasons, the recent shift in AIDS policy in Australia, towards “normalization” (Myszal, 1993), (whereby, AIDS and the reactions to it become part of institutional processes and policy), implies a move towards the individualistic, biomedical model. This from the preceding arguments could be seen as having the potential to be detrimental to policy formulation for AIDS.

AIDS as plague created a sense of urgency, but it served to initiate the concept that this was a disease of “others”. The policies developed at that time reflected the trend of containment and isolation. When AIDS became normalized as a chronic disease, it became embodied as a disease of “risk groups.” The sense of urgency waned and AIDS became a problem of medical management. Policy was directed towards the treatment of symptoms and the thorny question of screening was widely debated (and continues). The labelling of AIDS as plague or chronic illness has constrained and simultaneously enhanced the response to the epidemic. As Fee and Krieger (1992) comment each (of the labels) “has invited us to think and act in particular terms, using concepts and approaches shaped by past periods in history.”

AIDS with its global nature has challenged the distinction of disease patterns between the first and third worlds. No longer are infectious diseases the province of the developing world as demonstrated by the re-emergence of tuberculosis. Chronic diseases are not confined to the developed world, for as stated in the report for the World Bank in 1991,

chronic disease exists in the third world. This raises questions about the place and definition of disease and its role in the economy and the interdependence of nations world-wide.

AIDS forces the re-examination of the models used to define and interpret disease and the social and political mores used in their application. It demands the need for social reform and reminds us that health and disease are issues that have more than one solution; like AIDS the solutions are multifaceted and policy responses will be required to reflect the nature of the disease.

3:5 Response of the Health-care Services.

Research and surveillance are mechanisms which support and assist in all levels of health care provision, from all aspects of preventive and promotive education through to clinical decision making. It is notable that research and surveillance are inter-related, one supporting the other. Research tends towards the empirical, whilst surveillance tends to be about using and reporting upon established data. In the AIDS epidemic, monitoring of routine statistics gave the first clues about the spread of the disease, the groups affected and the presenting features. This surveillance still provides vital information about the spread of the disease, allowing educative programmes to be tailored to the "at risk" groups. This was a tried and tested method and one that was to be applied to the AIDS epidemic. This was embodied in the public education programmes in the US and the UK, throughout the 1980s.

Health-care provision can be seen as having centred upon the clinical management of disease. However, the wider aspects of education and prevention have rarely been so fundamentally linked to clinical treatment and given equal status as they were in the AIDS epidemic. It is notable that preventive and education programmes have been hampered by several barriers including the following:

1. Fear of active discrimination of minority groups for example, the gay population. This is particularly the case when these groups were the main focus of health education programmes. This has been fuelled by sensationalist reporting (and labeling) in certain quarters of the media (Tiffen, 1981; McGuinness, 1991).
2. Public fears, misconceptions and ignorance over the disease. This can be viewed as a reason for developing education programmes in the first place, to try and overcome irrational fears. However, long held prejudices are difficult to overcome and can act as a barrier to education programmes.
3. An initial misconception over the scale and nature of the disease by health care professionals.
4. Discussion of a topic so inextricably linked to sex and sexuality caused initial censorship of explicit "safe-sex" information.

In the United Kingdom the initial response came from health authorities in high prevalence areas and involved the setting up of hospital based specialist services. These hospitals gained reputations as "centres of excellence" and people from a wide geographical area attended them. In the early days of the epidemic there was a need to provide for a client group for which there had not been time to plan (Platt, 1987). Services developed on an 'ad hoc' reactive basis, in areas where there were significant numbers of people affected.

It became apparent that as more people sought care that the costs of in-patient care were increasing. There were continual advances in the treatments available and a growing awareness that people with AIDS would prefer to be cared for at home. Consequently, the demand for community care grew. The response of most community care providers was to attempt to use generic services (Bebbington & Warren, 1988; Beardshaw et al 1990). This approach was particularly successful in areas where staff who had client contact were given

appropriate preparation (Cotton & Kumari, 1990). There were a number of hospitals which established specialist HIV/AIDS community support teams (Lempp et al 1990; Smits et al 1990) which have been seen to provide valuable services (Baskerville & LeTouze, 1989; Smits et al 1990; McCann, 1991).

The development of statutory services was accompanied by a rapid voluntary response to the AIDS epidemic. In the UK voluntary groups have been involved in political lobbying, campaigning, bringing to the fore specific issues and initiating self-help strategies in relation to HIV/AIDS (Green 1989). Voluntary agencies, such as the Terrence Higgins Trust have played a major role in the provision of care. Most relied upon volunteer labour and in this respect, they reflected the approaches adopted in the United States.

The British Government has been clear in its support for models of care that involve and incorporate voluntary agency participation, both in general (Dept. of Health, 1989) and specifically, for people with AIDS/HIV (Fowler, 1987). However, doubts have been raised as to whether the American models can be replicated in the UK, and the length of time that voluntary participation can be maintained. Voluntary organizations have made it explicit that their services are not intended as substitutes for statutory care (Hart et al 1990), but should play a complementary and integrated role (Rayner & Grimshaw, 1988). In the UK, the state welfare system means that all persons are able to access health care and social care benefits. Indeed, under the Patients' Charter of 1990, all persons have the ability to choose their site of health care. No costs are directly incurred by the individual.

Berridge (1992) suggests that there are three distinct policy phases for AIDS in the UK. The first phase during 1981-6 saw the slow growth of AIDS into a national policy issue. This was a time when policy was formed from a "bottom --up approach" and there was the formulation of policy at a local level between gay and medical communities.

The second phase (1986-7) was as a period of "war time emergency" (Berridge, 1992). AIDS was viewed as a clear political priority. It was more than simply a policy matter for the Department of Health, sections of the community were placed in a state of emergency. The Chief Medical Officer (of the time), Donald Acheson, commented that AIDS was the greatest threat to British society since World War 11. This comment served to pave the way for the feeling of national crisis.

The final phase was a time of "normalisation" where AIDS and the reactions to it became part of the institutional process and normal policy. AIDS changed in nature, even in terminology, becoming HIV disease, and moved from an acute, infectious disease, to a managed chronic disease. The panic subsided, public interest declined, official institutions were established and formal procedures adopted. Paid professionals in many instances replaced the earlier volunteers.

The patterns of health care in the USA are vastly different to those of the UK and Australia. In the US the patterns of care for people with AIDS were created largely out of demand and voluntary endeavours. The formations of the Gay Men's Health Crises Centre in New York and the "Shanti " project in San Francisco are both examples of the active work of the Gay community (Shilts, 1987). The setting up of AIDS clinics in high prevalence areas was to become, for some medical practitioners, a lucrative venture (Caulfield & Goldberg, 1993).

In the US health care funding is dominated by the use of disease classification systems. This has had a wide reaching social impact for people who are HIV infected. From the beginning of the epidemic, the focus was on CDC defined AIDS (Crystal & Jackson, 1992). This has had major ramifications within the health and social benefit system. Persons with HIV disease who have not attained the CDC criterion receive separate and unequal treatment in qualifying for public health care and financial benefits (Crystal & Jackson, 1988). Unlike those who have defined AIDS, they are not presumed to be disabled for purposes of benefits determination, but are subject to a lengthy "per case"

determination, a process that has the potential to outlast the applicant. Social Security Administration benefits like Social Security Disability Insurance payments (SSDI) and Supplementary Security Income (SSI) are often crucial payments for those who are enduring the disabling effects of the disease (Crystal & Jackson, 1992). Medicaid is also tied up to the disability determination process, typically it is given to all SSI recipients. At the end of the process, those with HIV disease but not AIDS, may or may not succeed in gaining access to basic survival benefits. This unique approach to health care financing creates separate classes of ill people. One such class has access through Medicare to publicly financed benefits without means testing. This class includes the elderly and the severely disabled; the latter are subject to a 2 year waiting period which in effects bars AIDS patients. Another class, those who are disabled, are eligible for income benefits, and eligible for Medicaid (on a means tested basis) but not Medicare. The third category are likely to have difficulty accessing even means tested benefits. In this system, those who are long term disabled are seen as medically deserving. While others are consigned to the vacuum of conditional deservedness. The third group are "self pay " and, if not privately insured, have the potential to become part of a hospital's bad debt. Therefore, those not "officially" disabled by HIV/AIDS and without health coverage are likely to experience frustration in their attempts to secure medical care (Crystal & Jackson, 1992).

In the US the definitions of the disease shape the experience of the health care system, especially for those with HIV, not AIDS. This system assumes that many of the conditions of HIV disease are less disabling than AIDS and the care needs created are less severe.

In terms of policy development, there was a "bottom --up approach." Indeed it was not until the death of Rock Hudson in 1985, that President Reagan publicly mentioned AIDS, despite the fact that by this time "some 36,058 Americans had been diagnosed with the disease; 20,849 had died" (Shilts 1987:596).

Currently available interpretations of the development of AIDS policies in the UK and the USA have advanced two broadly different forms of explanation. AIDS has been

characterised as an opportunity for the populist New Right governments of the 1980s to push back the moral frontier. Government reaction, underpinned by the gay plague reaction of the popular press, was slow because initially only gay men were affected; high level intervention came only when the threat to the heterosexual population became clear (Weeks 1989). Another form of explanation comes in a cross-national comparison of AIDS policies in the UK, USA and Sweden. In this view, neither right wing ideology nor public opinion had much effect. Policy, as in almost all health arenas, was dominated by the traditional liberal, bio-medical elite. AIDS was a classic example of top-down policy making; government sent signals about the preferred consensus reaction into the public domain (Fox, Day & Klein, 1989; Day & Klein, 1990). The emphasis in both interpretations is on the period of high level government interventions, either in examining why it was delayed or in analysing why it came about.

3:6 Current Service Responses in Australia

To date, current service provision has centred upon the following:

1. National education programmes aimed at informing, in order to reduce risk and to prevent further spread. There has been a reported level of success in behaviour modification in specific groups, particularly in the gay community (Burcham et al. 1989).
2. Specific programmes, such as needle exchange programmes, telephone counselling and help-lines.
3. The establishment of centres specific to AIDS care, for example, the AIDS/HIV Unit at St. Vincent's hospital, Albion Street Clinic, both in Sydney and the Fairfield hospital in Melbourne.

Diagnosis of HIV/AIDS has largely been through self-referral at specific centres, STD clinics and family doctor services. There is no specific screening programme. However, the Commonwealth funds the National Reference Laboratory that is charged with "Maintaining a quality assurance programme for HIV testing including evaluation of test kits and monitoring of HIV testing throughout Australia" (ICGA 1993:53).

All persons applying for entry visas for longer than six months are required to undergo screening for the HIV virus. Current policy states that a positive result will not automatically exclude applicants. However, Paterson (1992) noted that this measure is the only 'national initiative' at present, in terms of screening.

Treatment of infected people has been reactive in nature, resulting in:

"...a significant disparity in the management of infected people in different States. An important consequence of this situation is that more and more people are travelling to the capital cities for treatment, particularly Sydney and Melbourne" (Working Group paper no.6 1989).

Medical treatment centres upon the development of protocols, the use of therapeutic drugs, and the development of new drugs to halt or slow the damage to the immune system. Counselling, psychiatric and social services all play an important role in the support and treatment of infected persons and their families.

The epidemic has exposed the fragility of personal-support networks that are frequently promoted as substitutes for services provided. Personal ties come under extreme scrutiny and strain when a partner is diagnosed as being HIV infected. Many of the initiatives in AIDS/HIV care and education have come from the voluntary sector and have been funded through charity and philanthropy.

As knowledge about the potential impact in population terms increases, there is a growing need to measure the utilisation of health care resources of those with HIV/AIDS. This

information will support the development of an effective mechanism for planning the provision of future services. In the author's previous experience of AIDS care in the UK, due to the reactive nature of the service provision, there was a plethora of services, but little coordination amongst the various bodies and institutions providing care. Exploration of the link between services as perceived by both the recipients and providers of care will be a fundamental part of the results of this study.

3:7 Australian Federal Response to AIDS/HIV

Altman (1992:55) argues that AIDS is "the most political of diseases.". This is based upon the concept that any new transmissible and fatal disease, which requires prevention strategies, which in turn have the potential (and need) to impact upon the intimate and private behaviour of individuals, would be politically volatile. The epidemiology and demography of AIDS has meant that particular communities have demanded participation in healthcare decision making to a level that was previously unknown. In doing so, they have called into question the established systems of medical authority.

Health in Australia is an area where responsibility is divided between Federal and state governments. The Commonwealth accepts basic responsibility for funding, while the states control hospitals and much of the basic policy, such as needle exchange initiatives, AIDS/HIV education in schools and health care provision at the local level.

Due to the political diversity of the state governments, there has not been a uniform response to the AIDS epidemic, particularly in relation to issues such as testing, notification, prostitution, homosexuality, censorship of educational materials and the prohibition of illicit drugs. The diversity amongst the states resulted in a variety of responses. For example, in Queensland, all the names of those testing HIV positive are collected, whilst in Victoria there are strong legislative guarantees of confidentiality. The laws in each state regarding homosexuality are also different. In Tasmania, for example, homosexuality remains illegal.

According to Altman (1992:62) the division of power has not proved to be a hindrance in the development of a National AIDS policy, however, there has been "buck passing between Canberra and State governments, particularly as costs of treatment escalate." It has been through a series of cost-sharing arrangements that the Commonwealth has sought to maintain a national AIDS policy. The Commonwealth has compelled all state governments to provide funding for community based organisations and education programmes, whilst the Commonwealth government has made funds available under the Matched Funding Programme (MFP). Interestingly, Altman (1992:62) claims that "there is conflict existing between not only the State and Federal governments, but also between the various sections of the bureaucracies." This according to Altman has been an ongoing problem in determining policies for prisons and Aborigines, although in the case of the latter, the White paper of 1990 did establish the need for some priority in education programmes.

The activity of community groups led to the formation of AIDS Councils, during the period 1983-84, where the community groups (in the main representatives of the gay community), and sections of the medical profession were established as key groups in AIDS policy making (Ballard, 1989). At the same time period, the Federal Minister of Health (Blewitt), had created a double institutional structure which according to Mistzal (1993:87) "was designed to reach a compromise between [the Federal government's] various commitments." This was composed of two advisory committees. One favoured social and community based strategies (the National Advisory Committee on AIDS {NACAIDS}) while the other leaned towards scientific and public health measures and was comprised of mainly medical specialists (the Task Force). By 1988, following a period of immobility and internal conflict, especially over issues such as screening, and education policies, the Federal government introduced organisational changes. The result was the dissolution of the previous committees (McGuirl & Gee, 1985) and the creation of a new body: the Australian National Council on AIDS (ANCA).

Concurrently the state AIDS councils have become recognised as state-funded providers of services, education and advocacy. In addition to the eight state and Territory AIDS councils, the Federal government has encouraged the establishment of the Australian Federation of AIDS Organisations (AFAO), as a way of establishing a core group with which it could negotiate. The AFAO which is funded centrally, represents the community sector nationally. It publishes the National AIDS Bulletin, which is recognized as an important medium for AIDS information in Australia. The AFAO also includes three national bodies: the Australian IV League (AIVL), the Scarlet Alliance (sex worker groups) and the National People Living With AIDS Coalition (NPLWAC). There is one national group that is not represented on the AFAO, the Haemophilia Foundation. This group has retained a separate status and is guaranteed core funding through the Federal government (IGCA 1993).

In 1989, the publication of the "National HIV/AIDS Strategy" established a framework within which all subsequent federal and state initiatives were to take place. The paper defined the two goals of AIDS policy as being "...to eliminate transmission of the virus; and to minimise the personal and social impact of HIV infection." The paper was published as a result of consultation with all the relevant national bodies and professional groups and "endorsed the partnership between government, health professionals and community -- based organizations" (Mistzal, 1993: 87).

AIDS policy in Australia has been formulated through the consensus approach. This has been a route fraught with difficulty as the different interest groups have vied for position. The result has been a fragmented approach, which according to Mistzal (1993:92) has tended "to result in protracted and erratic debates, making it difficult to reach decisions acceptable to all major interest groups." The most recent Federal policy developments reflect a shift in emphasis towards "normalisation." This change reflects the government's attempt to specify choices in a rational way and to place them in the arena of the cost-benefit approach. It could be argued that the change in view is reflective of the options adopted in

the USA and the UK. Australia has been unique, in that although classed as a Pattern 1 country, there has not been the spread into the heterosexual population that was originally predicted. This "normalization" phase can be seen to mirror the approach taken in the UK from 1987- onwards. AIDS is now perceived as being part of the institutional process and can be managed.

3:8 Health Service Response in New South Wales.

In 1990 the New South Wales (NSW) Health Department published a document defining the roles of Area Health Services and Hospitals. The aim of the document was to provide planning guidance in relation to all clinical services and to discourage duplication of services.

The delineation of services is intended to ensure an equitable distribution of services, according to circumstance, across NSW. Service provision is graded from 0-no services to level 6-specialist HIV/AIDS centre with a leading teaching /research role. So far, services have tended to be concentrated in geographic areas of high HIV/AIDS prevalence.

However, the document recommends that all areas should be able to provide services up to level 4, where management is carried out by a physician with an "interest in AIDS and related illnesses." The following hospitals are all designated as able to provide level 5-6 care with a Supra-Area/Regional role: St Vincent's, Prince Henry, (both in the Eastern Sydney area, which has the highest prevalence of AIDS/HIV), Royal Prince Alfred, Royal North Shore, Westmead, Royal Newcastle. It is envisaged that all these hospitals would have the capacity to be self sufficient, in regard to both in and out patient services, for the geographical area that they serve. Throughout the state, Sexual Health Clinics (sometimes called the Sexually Transmitted Disease[STD] clinic service), receive funding through the MFP as part of the mainstream services.

It is notable that within the NSW health department an "AIDS" Bureau was convened specifically to assist and advise upon service development in regard to AIDS/ HIV. Within the Illawarra area, where the pilot study was undertaken, care is provided up to level 4, through the auspices of the Sexual Health Clinic.

The AIDS Council of NSW (ACON) contributes to the provision of services for people with AIDS and HIV. It assists in the funding of community support and care groups, such as "Anakali" that provides social, emotional and practical help to people with AIDS/HIV. This service enables them to remain in their own homes and consequently reduces potential hospital inpatient costs. Interestingly, the Anakali project is closely modelled upon the "Shanti" project of San Francisco. All volunteers are provided with one hour of emotional support per week. They also undertake two consecutive weekends of training on a wide range of clinical and emotional aspects of AIDS (Gold, pers comm).

There are education programmes aimed at the specific "at risk" groups. For example, the Gamma project targets bisexual /married men; men who use "beats." There is a wide range of projects. All are designed to target those individuals who are particularly vulnerable. These are all part of the on-going programme to counter and prevent the spread of AIDS (IGCA, 1993).

In New South Wales, there are currently some 32 primary (solely a needle exchange programme) and over 90 secondary (run in conjunction with another programme) needle exchange outlets. They exchange needles and syringes, distribute condoms and educational materials, provide education about safe sex practices and safe drug use (IGCA 1993). Safe disposal of used injecting equipment is advanced through the "Fitpack." This is a portable plastic container that has compartments for clean and used needles. The Fitpack was organised by the NSW Dept. of Health to address the problem of improperly discarded needles. In 1991-92 there was a return rate in excess of 60%; no needle stick injuries and few concerns about disposal were reported by the general public (IGCA, 1993).

All sex workers' groups in Australia are members of Scarlett Alliance, the national forum for sex worker rights organisations. In NSW, the Sex Workers Outreach Project (SWOP) operates under the auspices of ACON and is involved in education, outreach and welfare services in both metropolitan and rural areas. The Western Suburbs Hospital's Sexual Health Clinic runs a project, which aims to increase access to support and counselling for sex workers and their clients. The Sydney Sexual Health Centre has a programme that deals specifically with Asian sex workers.

The final element in care provision is through private community health care/home care. This includes businesses such as "Homecare", "Homeleigh", "the Sydney Home Nursing" service and other private nursing services. All of these organizations require payment direct from the individual and /or their carers. An estimation of the current use of such services forms part of this study.

Service planning is based upon two key elements: epidemiological information about the spread, nature, and communities affected, plus the ability of key groups to lobby for service provision. In NSW both elements are present in the planning process.

The Special Unit in AIDS Epidemiology and Clinical Research currently collects and analyses data on AIDS/HIV. In Australia, as in the rest of the world, the epidemic of HIV infection is largely monitored by the surveillance of persons diagnosed with its most advanced manifestation, AIDS. By December 1991 there were 3096 reported cases of AIDS. However, it is important to note that in a study by McNulty et al. (1992) of AIDS case reporting in New South Wales, there was an estimated 18.4% under-reporting. This was due to factors such as concern over confidentiality and the complexity of case definition. Another source of data that has the potential to assist in the process of estimation of the level of HIV infected persons, is the National Zidovudine Register. In addition, two of the MFP projects reported on in 1991-2 have particular relevance to this thesis, namely :

1.Maintenance and development of a computer database on HIV infection at the Albion Street Centre Research Unit, Sydney.

and

2.Maintenance of a disease surveillance database at the Sydney Sexual Health Centre.

During the course of study these research centres were consulted.

Whilst these are valuable sources of information, there remains a paucity of data on the various aspects of the epidemic, as follows: the level and rate of infection; the needs of those infected persons at varying stages of disease progression; and the potential and actual impact upon the health and social welfare systems.

3.9 Conclusion.

From the literature it would appear that AIDS has forced people to look to the control measures of the past. In general, this is appropriate. It can also be grossly misleading. Prior constructions of disease --of plague, of chronic illness-- have according to Fee & Krieger (1993:340) "simultaneously enhanced and constrained our understanding of AIDS and our response to this new epidemic. Each has invited us to think and act in particular terms, using concepts and approaches shaped by past periods in history".

It appears from the literature that each paradigm of disease carries its own assumptions, concerning such basic issues as aetiology, prevention and treatment. Although framed in biological terms, these assumptions nonetheless have a strong social core that cannot be divorced from broader social attitudes about individual versus societal responsibility. AIDS has repeatedly demonstrated that people cannot be dealt with as isolated individuals as they are in both the infectious and chronic disease models, but must be addressed as members of particular communities with historically determined identities. At various times these paradigms have demanded that either war be waged on a mass epidemic or else there must be containment of a chronic ailment. It can be argued that AIDS has challenged the narrow

taxonomies of disease classification, this new affliction has highlighted serious flaws not only in the application, but also in the assumptions of policy.

How AIDS has been viewed has largely determined the types of policy that have been created. These policies and services can be seen to be reflective of societal attitudes to the disease and those affected. It can be argued that the inextricable link with sexuality has caused particular reactions within communities. AIDS has in effect forced discussion of sex and sexuality in the public arena. It has also challenged the rigid distinctions made about infectious and chronic disease and has tacitly questioned the assumptions of diverse patterns of disease characteristic of the first and developing worlds.

The views of AIDS as "the gay plague" and as later a "just another chronic disease" are tangibly linked to the types of service provision that have been created. It is argued that these views will also impact on the way that services are provided as they are reflective of deeply held societal views. It is for this reason that this chapter is important as it has described the backdrop against which services delivered and policies are formed. The views and attitudes that have been described in this chapter, will still exist within sections of society and will affect the ability of those affected to access care. Conversely, these perceptions of AIDS will also impact upon service providers and policy makers.

Chapter 4: Health Service Access, Use and Costs.

Overview.

This chapter is the central focus of this thesis, it examines the ability of people who are HIV infected to access and subsequently use health services. The impact of living with a stigmatising disease is also discussed.

Access and barriers to healthcare are examined, in particular the barriers of discrimination and prejudice. It appears from the literature, that individuals are subject to criticism and "victim blaming." In the light of AIDS "how you got it " does seem to impact on the type of care provision and the attitudes of those delivering care. Historically, sexually transmitted diseases have been hidden and rarely discussed even, the services dealing with them were generally hidden from the public gaze. There has long been the association with "shame ". Fundamental to this discussion is the acknowledgment that persons with HIV are a marginalised group and this from the outset will impinge upon their ability to access and use health care services. AIDS has brought the sexually transmitted disease specialists into the forefront as key providers. No longer a "Cinderella" service, these health care providers have found themselves acting as "gatekeepers" to medical and social research, advisers to health authorities, governments and the public at large, in the midst of drug trials and in receipt of large amounts of funding. The concept of funding has brought to the fore the notion that delivery of health care to people who are HIV infected is linked inextricably with the competition for resources, within the health care system.

Prior to recent therapeutic developments, appropriate treatment for people with HIV/AIDS was generally only available in hospitals. To date, most estimates of **healthcare utilisation** have been based on inpatient care and subsequent expenditure. The literature has focussed upon the utilisation of healthcare only as it relates to direct care costs. It can be argued that the true nature of utilisation and subsequent costs are not being reflected.

Factors which influence the use of healthcare services include: attitudes of staff to HIV infected people; increasing trends towards community care; constantly evolving drug treatments. One trend of particular note is the increasing use of outpatient care, coupled with a reduction in the number of inpatient days (Beck et al 1994; Hellinger, 1992). The studies by Beck et al, (1994) and Hellinger (1992) have noted that the reduction in outpatient visits and inpatient stays have been off set by the increased drug costs.

In predicting the costs of AIDS, there have been particular problems with the **modelling of costs**. The problems, according to Pascal (1989:105), stem from the "newness of the disease and the special demographics of its victims." The concentration in certain groups of the population means that the costs of prevention are hard to predict. There is a unique pattern of cost-sharing results and conventional methods of estimating early mortality are questionable. A number of models are described in the literature ranging from the demographic to the statistical model.

During the course of the disease, the resource needs will be heavily influenced by the types of cases, that is the case-mix, to be managed. **Case-mix** is a measure which covers both medical and resource elements of care provision. The most widely used case-mix classification system is the Diagnosis Related Group (DRG) system. The DRG system in Australia is currently undergoing revision to be more appropriate and reflective of the clinical aspects of HIV/AIDS. DRGs payment is by case, with a different fee being applied depending into which DRG a patient falls. In designing case-mix measures, staging classifications have been developed, but they have centred upon the end stage of the disease - AIDS.

Costing studies thus far, are subject to a number of criticisms as follows: the majority of studies have been based in the US; they are concerned with the costs incurred after AIDS has developed and finally, summary cost figures have largely ignored variations in disease progression, treatment regimens and differences between patients over time.

The **impact on the individual** is also largely related to cost, not only financial aspects but also lifestyle, physical and mental health. Having to deal with a life threatening and stigmatising illness may be problematic, as it forces individuals and their families to confront sensitive issues, such as sexuality and privacy. Thus, if gay, the emotional and social costs for an HIV infected individual are potentially great. Practical issues include a decreasing ability to work, earn money and therefore, the income, home and status of the individual are affected. The impact of AIDS/HIV is not restricted to those with AIDS-- the sick and dying. The vast majority of those with HIV/AIDS will live with their condition for well over a decade, being asymptomatic for varying amounts of time.

Fundamental to this discussion is the acknowledgment that persons with HIV are a marginalised group and this from the outset will impinge upon their ability to access and use healthcare services. The role of voluntary care services is a vital part of HIV care and their importance is noted. Finally, the costs to the individual of having a life threatening disease, which also encompasses societal fears and prejudices is examined.

4:1: Access to services.

Health service use is affected by multiple issues not least the ability of individuals to access health services. People in socially and economically disadvantaged positions not only have a greater burden of disease, but they also have a greater disadvantage in terms of services, which is described as Hart's inverse care law (1972). Krueger et al (1990), in the United States, noted that when all other factors were controlled including income prior to and after infection, it was those individuals who were in the lowest income bracket who were most likely to be HIV positive.

Access to healthcare can be defined in terms of equal access for equal need. This is not to say that all persons would be required to have equal use for equal need. This would, as a concept, severely infringe upon the ability of individuals to have choice in attaining health care. There is also a point at which equal access does not have to be tied to need (as a concept all people should have equal access to healthcare regardless of need) and in a way that is different from use (Mooney 1994). Ideally, healthcare services should be available to all persons but they will be accessed and used differently depending upon the needs of the individuals or groups. At the most basic level of the healthcare process as a system, there is a system which has equal access for all, should they require healthcare. There are times when it is appropriate to link access to need (Donaldson & Mooney, 1991). For example, when setting up funding for healthcare on a geographic basis, to maintain the idea of equality of access, for those who are HIV infected or diabetic or whatever, at that point it would be necessary to take some account of the needs in different populations. Access more than use will, according to Mooney (1994:85), advance the cause of equity in policy circles. Variations in access will determine the equity of the healthcare system.

Access to services is an important issue when assessing HIV -related service provision. That marginalised groups have less access to appropriate services has been demonstrated in the past. In industrialised countries, HIV/AIDS has predominated in disenfranchised

groups, namely, homosexual men, injecting drug users, and the poor, particularly women of colour.

Initially HIV became established in Australia in homosexually active men, Ross (1994:331) notes that this has lead to an "erroneous and dangerous assumption among IDUs and health educators that contaminated injecting equipment is the only significant means of transmission of HIV" (as those infected will only be HIV positive men). In an earlier study, Ross and his associates (1992) noted that the distribution of HIV infection in IDU men was around 3% for the heterosexually active, 12% for bisexually active, and 35% for the homosexually active, confirming that it is the sexual route which has infected most of the HIV seropositives.

In Australia, by the end of December 1992, a total 16765 cases of newly diagnosed HIV infection had been reported. Most diagnoses were amongst males and exposure to HIV was attributed to male homosexual contact for more than eighty percent of of cases for which information was available (McDonald, Crofts, Blumer et al 1994). McDonald et al (1994) noted that there were were relatively small numbers of HIV cases which could be attributed to injecting drug use or heterosexual contact. This is supported by the findings of Kaldor, Elford & Wodak et al (1993) who noted that there was a low prevalence of HIV infection documented in female and heterosexual male injecting drug users. These patterns are further substantiated by the work on pregnant women (McLaws, Brown, Cunningham et al 1990), surgical patients (Reid, Kaldor, Lord & Cooper, 1993) and blood donors (Kaldor, Whyte & Archer, 1991). Therefore, in Australia homosexual men are the majority group affected, with injecting drug users, being a group of concern as their illegal practices may influence their ability to access care {although the prevalence among IDUs is equal or less than five percent of the total HIV population, in those who did not have male-to -male sex (Kaldor, Elford & Wodak et al (1993))}.

Men who have sex with men are the group most heavily affected by HIV and AIDS in industrialised countries (Johnson & DeCock, 1994). By the year 2000 in industrialised countries, the current ratio of those infected with HIV presently accounted for by 60-80% adult males, with 20-40% among women and children (Ziegler, Feingold, Laufer et al 1991), will have reversed. Globally, the spread of HIV by heterosexuals will likely represent 75-80% of HIV transmission in the 1990s, predicts Dr J Mann (as cited in Corea 1992:327).

At the time of writing it would appear that homosexual men and injecting drug users, are the key affected groups in Australia, in regard to HIV. However, it is acknowledged that women and children are a group who are at a disadvantage as regards receiving healthcare (Bates & Linder Peltz, 1990), due in no small part to the attitudes of a predominately male dominated medical profession. Broom (1984) comments that women are seen as the consumers of health services and men as the providers and this view impacts upon the ability of women to access care. Finally, in Australia the problems already faced by the Aboriginal population in accessing care and the potential for the spread of HIV into that population is an issue for concern. Although beyond the scope of this thesis, these issues are acknowledged.

It is postulated that access to care will be determined by several factors, such as the attitudes of health providers towards HIV infected individuals; resources available; issues of confidentiality, discrimination and stigma.

In Australia, according to Ross (1994), homosexual men are discriminated against both socially and in some areas (for example, Tasmania), legally. Ross in 1986, following a discussion of political and social factors, argued that the level of social stigma affected the health and healthcare of homosexual men. Health practitioners may (inadvertantly) exhibit anti-gay attitudes which will affect delivery of care and will cause a reluctance on the part of gay men to attend these practitioners. Regardless of age the first contact for most

individuals with the health care system is their general practitioner (GP). Research studies show that gay men have particular concerns related to anti-homosexual feelings from doctors (Wadsworth & McCann, 1992), nurses (Getty & Stern, 1990), and healthcare providers in general (Paroski, 1987; Hellman & Santon, 1989).

It has been suggested that GPs are in a prime position to counsel patients presenting with psychosocial problems (Rowland et al 1989). However, many gay men do not attend their GPs through fear of a breach of confidentiality, a prejudicial approach (Milne & Keen, 1988; Boyton & Scrambler, 1988) and a lack of knowledge on the part of the GP (Gazzard, 1991; Boyd et al 1990; Wadsworth & McCann, 1992). Clarke in 1993, noted that few GPs have had the relevant training and experience in the healthcare needs of gay men.

Pauly and Goldstein (1970) reported that out of 1000 medical practitioners, 750 of them acknowledged that knowing that their patient was a homosexual, adversely affected their medical management of the individual. This is further supported by a study of psychologists perceptions. Davidson and Friedson (1981) noted that knowing a male was homosexual affected these psychologists perception of the individual and all subsequent opinions and treatment of the individual centred on their sexual orientation.

To date, studies of nurses, physicians, dentists and other healthcare professionals have suggested relationships between specific attitudes and a diminished desire to treat HIV positive patients (Henry, Campbell & Willenberg, 1990; Boland, 1990). Specifically, the data suggest that variables such as homophobia (Forrester, 1990), fear of occupational exposure (Wallack, 1989; Alexander & Fitzpatrick, 1991) and negative attitudes towards IDUs, are related to an unwillingness to treat HIV infected individuals (Kelly, Lawrence, Smith et al 1987; Prince et al 1989; Kunzel & Sadowsky, 1991). These findings have implications regarding the quality of medical management and the narrowing of the perceptions of the individual to concentrate upon their sexual orientation and lifestyle, which may be detrimental to the level and type of care that the individual can expect.

Some gay men have reported that they fear a breach in confidentiality by health professionals, which could impact upon employment, housing or future healthcare (Getty & Stern 1990). Watney (1990:30) claims that many gay men "opt for the HIV antibody test as a means of access to good patient management". As the HIV test is available from sexual health clinics on an anonymous basis, there is less to fear in terms of recrimination, discrimination and identification. It also serves as an access point to services, specifically related to sexual health and the treatment of venereal disease (Waddell, 1993). Whilst it may be stigmatising to be seen attending a sexual health clinic, the benefits of being treated there would for the individual outweigh the disadvantages, particularly in relation to confidentiality. Confidentiality is the essence of the *modus operandi* of sexual health clinics and hence the willingness of individuals to attend them when fearing a socially unacceptable disease.

Indirectly, stigma can lead to mental health problems. Ross (1990) studied life events and mental health in Australian homosexual men and found that for normal life events, stigmatisation amplified the level of emotional distress reported. The study by Ross (1990) supported the convention that the more socially disadvantaged, the greater the impact on life events. The study also found that those with HIV/AIDS had the greatest negative mental health consequences.

The studies to date would seem to indicate that access to health services is dependant upon the levels of care available, and the attitudes of those delivering care. There are recognised problems which relate to stigma, prejudice and discrimination. For the individual seeking care, the subsequent mental health consequences of dealing with such a complex milieu can impact upon their ability to access care, at various levels (Burnard, 1993).

Similar considerations attend the ability of IDUs to access care, although they are in most areas even more socially stigmatised and more legally disadvantaged (Ross, 1994).

Adequate medical services for IDUs are likely to be even more difficult to access.

According to Stowe et al (1992) it is a myth that IDUs use health services in order to obtain drugs. They use health services to access the same range of services that non-IDU people use. Roche, Guray and Saunders (1991), found that most medical practitioners were antipathetic to IDUs, wanted nothing to do with them and did not want to become involved in their treatment. The typical response to IDU patients was to refer them to a specialist clinic. It is apparent that most IDUs cannot expect, under such circumstances, to access optimum care and when coupled with a diagnosis of HIV, their ability to utilise the health services may be further impeded.

The social context of injecting drug use is a major determinant of the HIV-related harm that may ensue. It is assumed that IDUs are so socially deviant or disorganised that individuals are unable or unwilling to reduce their risk and the risk to other people (Chelwynd, Chambers & Hughes, 1993). The stereotype of IDUs being uninterested in their health and living only for their next "fix" may be according to Ross (1994:330) "as much a function of the milieu in which they exist as of their addiction."

In Australia, the "harm reduction model" has been promoted to reduce HIV transmission in IDUs; this model uses a multi-step approach which enables the individual to reduce risk at whatever level they feel capable. This has resulted in a high percentage (75%) of new needles being used to administer opiates (Australian National AIDS and Injecting Drug Use Study, 1991). Therefore, there are services which IDUs can (and do) access, ranging from treatment centres through to education and equipment to minimise risk.

The anecdotal relationship between early access to and the use of HIV-related service and improved survival patterns has been acknowledged for some time but direct evidence of this relationship is only now becoming available (Beck 1993; Peters 1993). This evidence, in conjunction with the different mortality patterns from time of AIDS diagnosis which have been observed across Northern, Middle and Southern Europe (Lungren 1993), suggests that

delayed access to HIV -services is also a problem in certain regions of Europe as well as in the US health care system where it is more widely recognised (Beck, 1994).

A final factor which will influence the ability of individuals to access care is the competition for resources. Silverman (1989) noted that genito-urinary medicine and allied medical practices have moved from being "Cinderella" services to well-funded, high status work. Before the advent of AIDS, work in Sexually Transmitted Diseases (STDs) was poorly resourced and had little political impact (Silverman, 1990). Since AIDS, these professionals have found themselves in the spotlight, sought by the media, in control of resources and in the midst of complex drug trials (Davies, personal communication). The role of the STD specialist has become as much political as clinical; fighting to obtain anti-viral drugs, acting as advisers to health authorities and government and acting as gatekeepers for medical and social research.

It could be argued that AIDS has created a major struggle for the increased resources, within the various medical disciplines. For example, genito-urinary medicine may fight with virology/ immunology for outpatients, so it can struggle for beds for AIDS patients with chest physicians. As one London doctor put it, "Whose virus is it ?" (cited in Silverman, 1990:211). This scenario creates problems at the most basic level of health care, as unless care is co-ordinated from a central point, the individual accessing care will find that services are duplicated and /or missing. For the individual, coordination of care by the professionals will be fundamental not only for access, but also for the efficient delivery of services.

4:2 Utilisation of Health Care Services.

The recent trend towards community care, in particular the care of the terminally ill in their own home (Heseltine & Leedon 1987), coupled with the rapid movement towards outpatient care, and the constant development in prophylaxis for opportunistic infections (Leidl, 1989; Gail et al 1990; Levine 1990; McCormack, 1990), makes it imperative that the extent of outpatient, hospital use and community care sector utilisation be determined for the HIV/AIDS population. Prior to recent therapeutic developments, appropriate treatment for people with HIV/AIDS was generally only available in hospitals, while now such care can be provided as effectively in nursing homes and often in the patient's own home (Andersen et al 1990; Beresford, 1989; Levine 1990).

The sick role, which is detrimental to the patient's well-being between crises, is also de-emphasised by non-hospital care. "The chief business of a chronically ill person is not just to stay alive or to keep his symptoms under control but to live as normally as possible despite his symptoms and his disease" (Strauss 1986:98). Notwithstanding the ability to provide care elsewhere and the psychological value of "step-down" care, the hospital remains the primary site for the treatment of the illnesses associated with the syndrome (Widman et al 1994).

Even if it is assumed that all hospitalisations for AIDS patients are necessary to the provision of acute care, patients are likely to remain hospitalised beyond the acute stages of disease (Andrulis & Beers, 1988; Andrulis et al 1989; Levine, 1990). Widman et al (1994) noted that there were several barriers which hindered the discharge of AIDS patients to the community. If there was a discharge planner, then there appeared to be a smooth transition back into the community. However, physicians were the group of professionals who were least likely to facilitate access to community care. Therefore, if an individual was under the control of a physician alone, then their length of stay was longer. The study by Widman et al (1994) was conducted in the US and whilst it reflects certain cultural aspects which are

pertinent to that country, it has merit in its general findings regarding delays to discharge. Professionals appeared to make decisions about who deserved care. Widman and colleagues (1994:65) found that "the concept of who is "blameless" in acquiring AIDS may be affecting agency decision making". The source of acquisition of AIDS is mentioned as being related to discharge delay; with those who acquired AIDS through injection use, inappropriately hospitalised. This was due to weaker support networks to facilitate discharge and the reluctance of healthcare agencies to provide services to a population that is seen as difficult to handle (Andrulis & Beers, 1988; Cotton 1988; Marazzi et al 1994).

In relation to community care, Ball and associates (1990) noted that the number of AIDS cases in the community had a potential impact on the availability of services and delays in arranging them. Other factors which impede community care include: a lack of suitable facilities and services; appropriate and sufficient public and private (personal) funds to pay for care that does exist; few individuals who are properly trained to provide care and social support (Andersen et al 1990; Andrulis & Beers 1988; Beresford, 1989; Levine, 1990; McCormick, 1990; Shulman et al 1990), and the structural inadequacy of community residential facilities (architectural barriers, lack of structural resources for non self sufficient persons) (Tolley, Maynard & Robinson 1991; Crystal & Jackson 1989).

Beck (1994:522) reporting on the IXth International Conference on AIDS (ICA) in Berlin, noted that there were "substantial changes in the nature of service provision". There is a growing trend in both in industrialised and Third World countries towards outpatient based care, as opposed to inpatient care for HIV infected people. One group of people for whom such a shift might be seen as inappropriate are patients with severe AIDS dementia. Earlier in the epidemic these patients would have been hospitalised, but the findings by Clarke (WSB321 as cited by Beck 1994) demonstrate that they can often be rehabilitated and cared for in settings other than the acute sector. A number of papers as cited by Beck (1994:523) at the IXth ICA described the attempts to integrate care across the various health sectors

(Shelp, POD214025; Schaefer, POD214031; Nera POD214034) to date many of these schemes have been limited to high prevalence areas (Goetzenich, POD 344337).

Most estimates of healthcare utilisation have been based upon inpatient care and subsequent expenditure (Johnson, Adler, & Crown. 1986; Lafferty, & To et al 1988; Jager et al 1988; Choukron & LonsDonic et al 1988; Hellinger, 1988; Scitovsky, 1988; Andrulis, 1990). A study which tried to estimate both hospital and community costs, within a District Health Authority, was described by Rees in 1989. In this study the patient records were used to extrapolate costs from the hospital or district global costs. Patient costing in this way does identify the details of AIDS/HIV treatment and the number of days as an inpatient.

However, in this way only direct care costs can be identified. Costs cannot be easily determined in relation to areas such as infection control, research, counselling and testing, which for a condition such as AIDS/HIV infection, (particularly the final two mentioned), might be significant and costly in terms of overall service utilisation.

The estimates of treatment costs for a "lifetime "of a PWA in the US ranged from US\$27,751- US\$ 147,000 (Green & Arno, 1990; Scitovsky Cline & Lee, 1986; Hardy, Rauch, Echenberg, Morgan & Curran 1986). These costs were estimated from the insurance /purchaser costs.

The studies reviewed thus far have focused upon the utilisation of healthcare only as it relates to direct care costs and it can be argued that the true nature of utilisation and subsequent costs are not being reflected. Mor et al (1990: 18) argue that "utilisation information is further limited by the diverse and rapidly changing nature of the AIDS epidemic." They also highlighted that studies undertaken in one location, or amongst a homogenous group of patients, would have limited applicability with regard to utilisation patterns amongst different population sub-groups. Sisk (1987) noted that the disease was primarily affecting young men in their productive years and that they were experiencing

high mortality and an increased health service use. For these reasons, the impact upon healthcare resources and lost life years is likely to be considerable.

The treatment regime employed in the care of an individual with HIV/AIDS will also have an impact upon the regularity of health service use. For example, individuals taking AZT will need to attend healthcare sites frequently, in order to be monitored. Disease management on an out-patient basis, without the prescription of AZT, will result in a lower cost than if AZT is prescribed (Morton, McCallum, Parkin & Bhopal, 1993). This style of disease management on an out-patient basis is common amongst the homosexual group in the USA (Sisk, 1987; Kelly, Ball & Turner, 1989); reasons purported for this include the support networks available and the type of opportunistic infections experienced.

McKeganey (1990) noted that those individuals who were intravenous drug users, returned to or further abused illicit and prescribed drugs during care. Morton et al (1993), noted that for IDUs their pattern of care was a mixture of out-patient and ward attendances with long periods of admission. It could be surmised that the differences in service utilisation are a mixture of social factors, (for example, poor support networks) the type of opportunistic infections experienced, and as a potential by-product of their intravenous drug use.

Scitovsky (1989) suggests that overall IDUs are heavier consumers of medical care than homosexual or bisexual men.

The type of drug therapy employed may also have an impact upon services used. AZT has notable side-effects (Pinching, 1991). One of the most common is anaemia which can necessitate regular management with short in-patient admissions for severe cases. For a haemophiliac, an individual who already requires regular admissions, AZT and other drug treatments and indeed HIV/AIDS, has the potential to increase the frequency of healthcare being sought.

The use of expensive drugs to prophylactically prevent opportunistic infections, such as Acyclovir to prevent CMV, Fluconazole to prevent fungal infections and Pyrimethamine to prevent toxoplasmosis (Smith 1991), will also directly contribute towards the spiralling costs for care.

Overall in the light of recent work on drug therapies and with the anticipated introduction of new antiviral agents and the increased use of combination chemotherapy (De Clerq, 1991), the relative contribution of drug costs per patient year may well increase further (Hellinger 1992).

The work in the USA by Hellinger (1991) demonstrated that the number of people with HIV but not AIDS, was equal to approximately twice the number of people with AIDS (PWAs) receiving medical services. Similarly in the study across nine cities in the USA conducted in 1990, it was revealed that "for every person with AIDS at these sites, two additional persons with HIV were receiving medical services" (Farizo, Buehler, & Chamberland 1990:1798). It would appear that it is more appropriate to examine the treatment patterns and subsequent costs of those with HIV as well as those with AIDS. It is acknowledged that data capture on PWAs may be more reliable than data on persons who are HIV positive: those with HIV may be a more fluid group, and may well 'shop around' for their preferred treatment options.

The work by Beck, Kennelly, McKevitt et al (1994) carried out at a major London teaching hospital over the period 1983-89, suggests that for people with AIDS "the number of day case admissions increased while planned admissions decreased" (p 367). The authors of this study noted that there was a reduction, in the duration of inpatient days, for persons with AIDS and consequently costs associated with inpatient care have decreased. During the course of this study there was a shift from inpatient care to an outpatient based service, this according to the authors resulted in "fewer patients being investigated and treated in hospital and more as outpatients" (p 375). However, the overall reduction in expenditure

related to both in-and out- patient costs "was offset by the increased expenditure on drugs"(p376), this equates with the work carried out by Hellinger (1992) in the US who commented upon the ever increasing drug related costs.

It appears from the literature that there is information available in relation to direct care and inpatient costs specific to the care of people with AIDS. There appears to be no estimation of the costs of healthcare utilisation from diagnosis as HIV infected, through to death from AIDS. Although the work by Beck et al (1994) did incorporate persons who were HIV both symptomatic and asymptomatic, the study was only concerned with individuals attending one care site.

This study attempts to describe the utilisation of healthcare services and costs, for both direct and indirect care, in the hospital and community setting. There is an emphasis placed upon the description of care needs as outlined by the recipients and providers of healthcare. Other important factors which appear to be emerging from the literature, which have the potential to impact upon the study include : the type of patient, the management profile, the drug regime employed, the social support networks available to the individual and the coordination of care.

4:3 The Costs of AIDS/HIV.

4:3:1 Modelling the costs of HIV/AIDS

AIDS presents some remarkably difficult new conceptual problems in the modelling of disease costs (Pascal,1989). According to Pascal (1989:105) these problems stem from "the newness of the disease and from the special demographics of its victims". The concentration in certain groups in the population means that the costs of prevention programmes are difficult to anticipate. There is a unique pattern of treatment cost -sharing results (which rebounds back on the total costs of treatment) and conventional methods of estimating costs of early mortality on national output are called into question.

Hardy et al (1986) and Scitovsky and Rice (1987) estimated the economic impact of AIDS in the USA by means of empirical projections. They used epidemiological and available data from sources such as hospital statistics, medical insurance company data and social services. This is only one form of modelling using existing data to predict through a variety of mechanisms potential costs and utilisation of services.

The models described in the literature include the following: epidemiological models, (Jager et al.1991;Leidl et al 1992), statistical models (Wilkie, 1987; Brookmeyer & Damiano, 1989) and population projection models (Anderson, 1988; Dietz, 1988). Statistical models are empirical and have been used for short-term descriptive predictions. Population dynamic models are, on the other hand, used for long term projections, the fundamental difference being that they take into account the "transmission element which dictates the course of the epidemic" (Anderson 1988:12).

Descriptive utilisation models such as the one described by Anderson and Newman (1973), postulated that the utilisation of healthcare is a function of three types of variables: predisposing factors (for example, socio-demographic factors), enabling factors (for

example, financial ability) and illness level (for example, symptom intensity and functional disability). It is expected that these three variables will also influence health service utilisation by people with HIV infection.

All the models to date have focused largely upon the end stage of the disease--AIDS and /or have used a back projection method to estimate numbers infected. It is known that this allows for inaccuracy in the projected figures as the numbers infected may not be represented by those who have AIDS. The large variation in time, from infection until the development of symptoms and the variance between individuals in symptoms experienced, does call into question the usefulness of the back projection method. It is for this reason that there is a need for a prospective study from the time of diagnosis, as being HIV infected until the development of AIDS then till death, in order that meaningful estimates of future healthcare needs can be made.

It can be stated that the total needs for healthcare in any population for a specified period of time are going to be significantly related to the specific types and stages of infection/disease. Drummond and Davies (1989) have suggested that available evidence suggests that the initial costs of diagnosis and treatment of AIDS are high, followed by a period of low cost/low treatment levels. The costs of treatment increase as patients become dependent towards the end stage of the disease, making the cost curve for AIDS patients "U" shaped. However, therapies that change the time profile of costs also change the distribution of total costs. For example, if AZT alters the typical U-shaped curve for AIDS treatment into a J-shaped function (that is, because it alleviates early symptoms more effectively), then the public costs will grow, as patients exhaust their personal financial reserves during longer survival times and fall back upon the publicly funded system for support.

4:3:2 Case-mix and Diagnosis Related Groups.

During the course of the disease, the resource needs will be heavily influenced by the types of cases that is, case-mix, to be managed. Case-mix is a measure which covers both the

medical elements (like functional ability or diagnosis) and the resource elements (number of outpatient visits, days of inpatient care and so forth). Palmer (1989:324) describes case-mix as the "distribution of hospital patients based on a classification of morbidity and other characteristics, including aspects of the treatment they have received."

The most widely used case-mix classification system is the Diagnosis Related Groups-DRGs system, which applies only to hospital inpatients. The diagnosis related group system of categorising case-mix was first described by Fetter, Shin, Freeman et al in 1980. The DRG system defines the basic unit of service in any hospital as "the episode of care given to an individual patient during a single inpatient admission" (Thompson 1985 : 253). The DRG system is based upon the use of International Classification of Diseases (9th revision), Clinical Modification (ICD-9-CM) and comprises some 467 groups organised into major diagnostic categories. DRGs are a mechanism for classifying hospital inpatients into groups which are homogenous in respect of resource use, and contain patients with similar clinical characteristics. Currently in Australia, the Australian National DRGs (AN-DRGs) are being revised and re-developed, and the version used at the time of study is the AN-DRG v 2.

The AN-DRGs classification incorporates seven HIV DRGs in Major Diagnostic Category (MDC) 18: Infectious and Parasitic Diseases. Two of the seven relate exclusively to paediatric cases whilst this is the current version in use. It was anticipated that during the course of study, a new and more refined version would be available but at the time of writing AN-DRG v 3 was still undergoing revision, as more information on the disease became available. Leidl (1989:124) stated ..."that to define a case mix measure, HIV infected patients must be classified by the stages of the disease development." It is for this reason that the third version of the AN-DRG is under review and development. In a Draft report it was noted that

"the HIV classification structure is based upon a hierarchy to take into account that any one case could have multiple HIV related conditions; the hierarchy determines which

condition is to be used for AN-DRG assignment" (Australian Clinical Casemix Committee 1995).

"Case-mix is anything but constant" (Leidl,1990:17). Since the beginning of the AIDS/HIV epidemic, not only have the numbers of people seeking care been increasing, but the case-mix has also been constantly fluctuating. This, in turn has caused an ever increasingly complex pattern of care being sought by (now) diverse sub-populations. The spectrum of HIV-related disease has been shown to vary markedly in different populations (Rutherford, Lifson, Hessel et al 1990; Greenberg, Thomas, Landesman et al 1992; Munoz, Schragar, Bacellar et al 1993). Furthermore, the relative frequency of conditions, such as Kaposi's Sarcoma, can be significantly altered by a variety of measures, including behavioural changes (Schechter, Marion, Elmslie, Ricketts, Nault, & Archibald 1991), public health measures (Havlik, Horsburgh, Metchock, Williams, Fann & Thompson, 1992) or successful therapeutic interventions (Hirshel, Lazarrin, Chopard et al 1991; Kemper, Tucker, Lang, et al 1990). Montaner, Le, Hogg et al in 1994, noted that over a ten year period in Canada there was an " increasing incidence of emerging AIDS index diseases, that is opportunistic infections such as, oesophageal candidiasis, CMV, wasting syndrome, toxoplasmosis, and MAC disease" (p 695). Thus, the constant change in the index of the most advanced form of HIV infection -AIDS -will ensure that the case-mix will continue to change as the pattern and spectrum of disease changes.

Palmer et al (1991) described the treatment costs for HIV /AIDS individuals, by DRG classification, in seven major teaching hospitals in Sydney. The study noted the variation across the DRGs and the variation in costs between the categories and indeed, amongst the hospitals within each DRG category. The reasons given for the variations were as follows: differences in assigning individuals to their respective DRGs; different drug regimens; and differences in the philosophies of management of the disease.

The DRG system has been largely used in the United States to assist in the stemming of hospital inpatient costs. Payment has been by case, with a different fee depending into which category - DRG - a patient fell. According to Mooney (1994:157) there is evidence that "DRGing in the United States has reduced hospital costs per day and per admission. There is a degree of concern that at least some of this saving has been achieved, simply by moving patients out of the inpatient sector to other forms of care not covered by the DRG process". Donaldson and Gerard (1993) have expressed concern that the DRG process has reduced the quality of care .

There are some issues of concern surrounding the use of DRGs.

Firstly, the DRG initiative has expanded at rapid rate to form an international health service industry. Despite the lack of evidence, according to Mooney (1994:157), that there is "any convincing evidence that DRGing has resulted in an overall reduction of healthcare costs".

Secondly, DRG costings are average rather than marginal costings. DRGs are used as a means of estimating utilisation and subsequently contribute to the planning of future services. Therefore, it would seem more appropriate to use marginal costs as they would be indicative of the extremes. According to Mooney (1994:31) "the use of average costs could lead to the costings being wrong." If information from the DRG system is utilised in the planning process and specifically in priority setting, it could be argued that the use of average costs is a flawed mechanism. Marginal costs would assist in the reflection of the severity of cases, within each DRG, whilst average costs would not.

Thirdly, due to the current structuring of healthcare payments, the interactions of the doctor and patient take place within units defined and bureaucratically justified by the existence of real or presumed sickness. Cash flow is therefore controlled by physicians at the point of diagnosis, albeit indirectly. Rosenberg (1988:24) comments that diagnosis related groups "are a product and symbol of, and condign punishment for, the rigid and unresponsive aspects of a cost plus, disease legitimated system of payment. It is a system,

moreover, in which physicians and the values of scientific medicine have played a pivotal role."

Diagnosis related groups were introduced to assist in the rationalizing of scarce resources. However, rising costs highlight the fact that disease as experienced, comes in units of people and families, not of discrete, codeable diagnostic entities. It is worthy of note that the management of an acute episode of illness does not exhaust the possible universe of medical care options.

Finally, Mooney (1994) reflects upon the strange dichotomy of having the costs associated with each DRG, based upon the activity of the hospital, prior to the introduction of the DRG system. Mooney argues that the costing of DRGs on past performance "will allow, even promote, inefficient practices to be continued in the future"(p 158). Palmer (1989:329) does counter these comments by making explicit the fact that:" no previous case mix classification system used in economic or other studies of hospitals has been subjected to anything approaching the intensive scrutiny devoted to the DRG system".

Leidl (1989:124) stated "that to define a case mix measure, HIV infected patients must be classified by the stages of the disease development." It is now clear that the spectrum of HIV-associated diseases varies at different stages of HIV infection (Greenberg, Thomas, Landesman et al 1992). This information has been used successfully in the development of a variety of staging classifications (WHO International Collaborating Group, 1993; Montaner, Le, Le N, Craib, Schecter, 1992). There are several other classifications of AIDS patients available, for example, the definition by the US Centre for Disease Control (CDC), the Walter -Reed classification (Redfield, Wright & Tramont 1986) or specific AIDS -DRGs such as the one employed in the city of New York as part of the city's strategic plan for AIDS (Knickman, Gibson et al, 1988).

In attempting to define the economic impact and the resource utilisation of AIDS/HIV, classification of case-mix is an essential consideration in the assessment of the economic

impact of the disease. This is verified in the literature by the significant influence of case-specific resource needs have displayed (Fanning & Harman, 1987; Rees & Roberts 1988; Moien & Kozak, 1989; Palmer et al, 1991). This is initially true in the pre-AIDS symptomatic stage of the disease and secondly, by the variations in case-mix that occur over time as the disease progresses.

4:3:3 Costing Studies.

There are a number of criticisms regarding the costing studies carried out thus far. Firstly, as the majority of studies originate in the USA, it is postulated that they could be difficult to apply to the Australian situation, due to differences in disease management and levels of healthcare access. Secondly, they mainly concern costs incurred after AIDS has been diagnosed and according to Gray (1991), fail to provide a complete picture of the disease. Thirdly, the summary cost figures produced by many studies, such as the ones carried out by Seage, Landers, Lamb & Epstein (1990), ignore variations in the progression of the disease, treatment regimens and between patients over time.

Morton et al (1993), in the UK, reported upon the use of patient profiling to assess the costs of AIDS/HIV infection. The study of 24 randomly selected individuals was apparently successful in generating cost and service utilisation data, confirming that the greatest proportion of costs for this group derived from in-patient days and drug therapy. The authors of this study also acknowledged the existence of "potentially substantial non-NHS costs." (p 242). These included: patient lost earnings, cost of bereavement, the personal costs to family and friends; hospice care; life years lost; patient travel and housing costs.

It is apparent that the costs of AID/HIV extend beyond the boundaries of hospital in and outpatient care. Whilst the work by Hellinger (1992) does, in predicting future costs, recognise the need to include community care, this is an area which demands further

attention, particularly in light of the recent trend towards community care. There are acknowledged problems in the costing of such services (Pascal, 1989).

The majority of models of care are dependant upon varying levels of voluntary community care. It seems appropriate to estimate the costs involved in this aspect of care. Many authors issue dire predictions about the level of support currently being offered and the ability to maintain such services as demand increases (Sosnowitz & Kovacs, 1991; Arno 1989; McCann, 1990). It must be remembered that the voluntary systems were set up in response to crises and were never intended as a long-term option (Sosnowitz & Kovacs, 1991). McCann (1990) argues that much of the reliance on voluntary organisations has arisen as these organisations have provided choice and an addition to statutory services. It has been argued that they can react more quickly than statutory services which may find it harder to adapt to changing options in self-help, and may be more able to provide appropriate and acceptable care (Green, 1989; McCann, 1990). In terms of costing volunteer work, even if it was known how many hours such people devoted to a case, defined in terms of pathology, disease stage, patient group, location, and so forth there is still the problem of valuing those hours in social terms.

The socioeconomic status of PWAs affects the level of resources required to treat them. Firstly, according to Scitovsky, Cline & Lee (1986) in the early stages of the epidemic, there were differences in the pathologies displayed. Middle class homosexuals were more likely to present with KS, lower-class drug abusers- PCP, TB and meningitis. The latter tend to be more expensive to treat. Secondly, the IDU population and their infected associates often lack adequate residences for the receipt of home-care (Ronald & Robertson, 1992; Marazzi et al , 1994) and must be retained in acute facilities (Joseph & Roman-Hay, 1990; Raphael, 1990). Thirdly, middle-class patients have more access to volunteer networks for the provision of support services, which lowers nominal, if not real, costs for them (Arno, 1986).

The other critical cost -sharing issue arises from the strong geographic patterning of the epidemic. In Australia, the majority of PWAs are located in Sydney, with the other major cities having proportionate numbers. This has two implications: some states are facing much higher treatment funding obligations (for example New South Wales versus Western Australia) as are some local authorities, as they are called upon to provide social and support services.

Work to date into costs suggests that inpatient services account for as much as 90% of the treatment and care costs of people with AIDS (Lee & Arno 1986; Scitovsky, Cline & Lee 1986). The increasing use of outpatient care as reported by Beck et al (1994), reducing the number of inpatient stays, will have some impact. In a prospective study in Italy, of home care for people with AIDS (Tramarin, Milocchi, Tolley et al 1994), the authors found that overall, there were cost savings of some 6-7% relative to those persons who were receiving hospital based care. However, there were strict criteria regarding eligibility for home care and the authors did make comment upon the shift to the family and voluntary groups of care costs.

The recent work in the literature, regarding the effectiveness of AZT, must also bring into question the prediction of future costs. If AZT is eliminated from the therapy regime, then, in theory individual costs will reduce. Currently, the early treatment of individuals who are asymptomatic HIV infected is controversial (Volberding, Lagakos, Koch et al 1990; Albouker & Swart, 1993) also the treatment is not deemed to be cost -effective (Oddone, Cowper, Hamilton et al 1993).

Another significant factor will be whether the level of HIV antigens is an able predictor of HIV infection. The work already reported in this thesis regarding the possible necessity of estimating the viral load (a more costly and involved procedure than the current antigen tests), has the potential to significantly alter costs at the point of diagnosis.

All these factors serve to underline the need to examine the effectiveness of current therapy particularly in the light of the changing mortality and morbidity patterns (Peters, Beck, Coleman et al 1991; Coleman, Beck, Peters & Harris 1992) and the differing context of health care delivery (Beck, 1994) which has occurred since the onset of the epidemic.

Most cost studies, thus far, have been based on charges billed by providers and not on analyses of resources actually consumed by HIV patients. It is a distortion to assume that charges are the same as social costs. According to Pascal (1989:108)

"true cost estimates will be further obfuscated if we fail to take account of different degrees of capacity usage across communities, a difference that may be partly attributable to AIDS itself. That is, the true cost of a hospital bed-day is much lower in communities with excess beds than in one where the epidemic is beginning to stress the health care system."

Lifetime costs and cost shares are partly a result of policy decisions, notoriously subject to change as new facts amass or as political fashions shift (Pascal, 1989). But less dramatic and more technical policy decisions can have major implications for costs. These may relate to the definition of AIDS, definitions of disability and the coverage of services within a particular area.

More generally, there appear to be some basic choices in working out a societal response to the AIDS cost issue. These are as follows:

- Do nothing. Allow policies developed for other diseases to determine how costs will be shared.
- Attempt to shift more of the burden to the private sector. Reduce current restrictions on such items as private health cover to include those "at risk " of HIV/AIDS.

- Attempt to shift more of the burden to the public sector as a whole. For example, social and welfare payments being less restricted by definitions of such things as disability.
- Attempt to shift more of the burden to the federal level. Increase the federal share of AIDS -related treatment costs.

Decisions made on these points will relate to views held regarding how the burden should be distributed, (where notions of responsibility, ideology, federalism and so forth lie) and how the funds are raised to support the various sectors. This raises the spectre of wider economic consequences. Questions could be asked regarding how much product the nation will forego because of the increased morbidity and early mortality associated with HIV/AIDS. Presently, according to Pascal (1989) information on aspects such as age, education, occupation, experience, and prior earnings is insufficient to make estimates on the "income streams interrupted by the disease" (p111).

To what extent is the foregone product, in the case of AIDS a true social cost ? The groups affected in the majority of industrialised nations are homosexuals and IDUs. This means that unlike young coronary or accident victims, PWAs have few dependents. This means that they would have consumed most of the product they produced had they lived.

In places where demand for acute and chronic beds, and associated healthcare professionals, is concentrated, due to the prevalence of AIDS within a locality, prices could increase. In areas of high AIDS/HIV prevalence, it could be a possibility that the demands placed on social and health services by this group, would reduce the availability of services to other groups, such as the old, the homeless, and those with other chronic disease which render them dependent on care- in all its guises - professional, social and health.

The move to more care being provided in the community will also impact upon costs. In Rotterdam, a study carried out by Moons (1994) on the costs of specialised home care for

PWAs was not taken beyond the pilot stage as it became apparent that data collection on the costs of specialized home care was very complex. The estimation of the costs of community care would need to incorporate the costs of general practitioners, informal care givers, community agencies and the costs of specialized nursing care.

It would appear that the evolution of knowledge regarding treatment, the nature of the virus, the view that HIV can be a managed disease, and the knowledge that some social groups will incur different costs, are all factors that will affect the ability to predict costs. The cost burdens of the HIV epidemic are as yet fully unknown, largely due to the fact that the spectrum of disease is changing, as are treatment protocols. The social groups affected are also changing, particularly in industrialised countries where there is an increasing level of infection in heterosexuals and this too, contributes to the uncertainty of the cost of the disease.

4:4 The Impact on the HIV Infected Individual.

"In many ways AIDS is like other illnesses which devastate individual lives. What is remarkable about AIDS, however, it is not simply its virulence, but the weight of symbolic meaning that it carries" (Weeks, 1989:18).

The rapid growth in numbers of people with HIV infection and with AIDS has been perceived as generating a "crises" in health care systems (Silverman, 1990). Contemporary crises occupy a number of familiar sites, including the economic, the administrative and the scientific. In the case of AIDS, the perceived "crisis" has produced questions for each of these sites: how to meet the cost of health care, how to organize welfare and medical services, and how to find a vaccine and/or cure.

As Weeks points out, however, what is remarkable about AIDS is the symbolic meaning that saturates it. For the individual with HIV/AIDS this symbolic meaning will impact on

their social and personal life. The costs of AIDS/HIV will not be associated solely with the amount of resources utilised by an individual, but also with the social and symbolic weight attached to the disease.

Forstein (1984) noted that there is a growing social science literature on understanding the "social and personal course" of the AIDS disease process once it has developed. Case studies such as the ones undertaken by Minchiello (1992), note that individuals report a great deal of stress associated with learning to live with HIV. For the individuals in Minchiello's study, receiving news about HIV was perceived as a burden, because of the uncertainty of the meaning of being HIV-positive, and because of the need to come to terms with a shorter life and with death. Individuals need to make adjustments to life plans and to establish a new and stable identity within the limitations of a debilitating and highly stigmatised disease. Forstein (1984) suggests that there are four stages that an individual will pass through: an initial one of "shock and disbelief", followed by "denial", "bargaining" and "planning realistically for death".

Given the current knowledge of HIV/AIDS, one might assume that HIV-infected people would 'naturally' become depressed upon learning of their infection with a potentially lethal and stigmatizing virus. Yet, as with many chronic illnesses, this does not appear to be the case (Rabkin, Williams & Neugeberger et al 1990). Hedge (1994) identified factors related to successful coping with HIV, among asymptomatic men, as measured by an absence of psychological distress and high quality of life scores. The important factors were self-rated physical health and impact of life events together with low levels of perceived stress and good social support, rather than CD4 count or number of life events. Although social support has been implicated as being an important factor in limiting psychological distress, which aspects are involved and how it is conceptualised, are not always clear (Thornton & Flynn 1994). Hedge (1994) reported that lower levels of distress, as measured by the General Health Questionnaire (GHQ), were related to having a partner and a number of close friends.

According to Cotton and Kumari (1990:216), "discrimination is probably the largest single issue in AIDS, and the illness has become inextricably linked with male homosexuality". Disclosure of being HIV-positive is problematic for an individual who has concealed his sexuality from family, friends and employers. Schneider and Conrad (1990) have adopted the metaphor of "staying in the closet" to describe situations where people conceal their illness. The study by Minichiello (1992) reinforced the notion that concealment of the illness and sexuality went hand in hand. The fears of being ostracised by family and friends are not without foundation (Grief & Porembski, 1988), although it is not always the illness, but rather the sexuality of the individual which is the cause of alienation (Kelly, St Lawrence & Smith, 1987). Thus if gay, the emotional and social costs for an HIV positive individual are potentially great.

Practical issues surrounding being HIV positive include: the decreasing ability to work as the disease progresses, thus affecting the income and resultant status of the individual, who may no longer be in a position to pay for private health insurance, mortgages and so forth. Housing is an issue of concern as individuals may require to be rehoused because of homelessness, harassment, or where ill health constitutes a need to be rehoused to more suitable accommodation (Cotton & Kumari, 1990). Other issues concern travel to hospital appointments; accessing social, medical, and voluntary care; gaining comprehensive information about HIV/AIDS and finally receiving quality care from a variety of sources.

Other issues relating to the personal costs concern how individuals manage being HIV-positive. Taylor (1983) discusses how people confront life threatening illnesses by undergoing a five stage adjustment process. This involves the following themes: a search for meaning in an effort to understand the event; attempts to gain mastery over the event and to restore control over other aspects of one's life; and maintenance of self-esteem and equilibrium.

Finally, perhaps the most common misconception about the impact of AIDS among those who are infected is that it is restricted to the sick and dying. The vast majority of those with HIV/AIDS will live with their condition for well over a decade and they will be asymptomatic for varying amounts of time.

4.5 Conclusion.

From the literature reviewed to date it is apparent that there is a gap in the available information about the level of health care requirement for people who are HIV/AIDS infected. It is obvious from the literature that much of the work has been undertaken in the US and Europe, in regard to the epidemiological and resource use data available. There is information available in relation to direct care and inpatient costs, particularly in relation to the care of people with AIDS, but there appears to be no estimation of the costs of health care utilisation from diagnosis as HIV infected, through to death from AIDS. This study describes the utilisation of health care services and costs for both direct and indirect care in the hospital and community setting, as described by the recipients and the providers of health care.

As treatments for HIV/AIDS evolve and survival times lengthen, changes in the health care delivery system will have to occur. As no one sector of the HIV/AIDS care community can be totally responsible, sharing of the load will be essential. The extent of hospital and community care requires to be described for the entire spectrum of the disease, hence the need for a longitudinal study.

Throughout the literature, there seems to be the assumption that conventional medicine is the sole source of care. There are an ever increasing number of alternative therapies available and it seems essential to describe the level of use of these therapies by people who are HIV infected.

To determine the pattern of care, estimation of the met need and unmet need, the social, individual and health care impact of the disease is required. To study and describe any group of individuals prospectively will allow for evolution of therapies and the response to be estimated concurrently. Hence the impact can be described more comprehensively than if a retrospective study is undertaken.

It must be remembered that health care delivery is a complicated process which can be better understood if analysed in terms of some of its constituent parts. The broad areas which need to be considered are:

1. the type of services provided;
2. access to these services by patients requiring them, as well as the characteristics of those patients not using the services provided;
3. the effectiveness and efficiency with which the process of health care delivery achieves its implicit and explicit aims.

It is recognised that for a group as diverse as those with HIV disease, the aims of the health care system will have both a population as well as an individual perspective. Consequently the users of service as well as the providers, need to be involved when services are being designed.

Finally, in order to assess the effectiveness and efficiency of health care delivery, it seems necessary to combine the therapeutic and the physiological data on case severity with markers on service utilisation and their resource implications. Then it would be possible to create and define appropriate and optimal models of health care delivery. This approach would be applicable to other areas of health care delivery, particularly long term disease, such as diabetes.

Chapter 5 : Method

Overview

This chapter commences with an examination of **design issues**. This section commences with a discussion, that the measurement of need cost and utilisation are required to be addressed simultaneously, in order to be an effective means of service planning. The need for information on issues such as severity of illness and need are essential and a database is required that contains both types of information.

The context in which the research took place, that is, the study of HIV infected individuals, the majority of whom are gay men, being carried out by a non- Australian woman is described. People with HIV/AIDS are a marginalised group and it was recognised that there was the potential for conflict which would result in refusal to participate.

Research participation describes the participants and some of the potential barriers to individuals taking part in the study. The process of sampling is discussed and why the use of purposive, nominated and convenience sampling methods were deemed to be both necessary and appropriate to this study.

The methods of data capture chosen were determined by the research questions asked and more importantly were subject to the unique social circumstances and health of the respondents. The method of study selected was a longitudinal study and, although there are problems, such as attrition and recruitment, with a trend study, it was the appropriate mechanism to study changes over time. The pros and cons of the methods of data capture, using a questionnaire for recipients of healthcare and the interviews for providers are discussed.

Confidentiality is an issue which has the potential to prevent access to participants. It was necessary to ensure confidentiality from the beginning of the study design through to the final execution. The confidentiality of respondents, and of the data, was ensured at every stage of the study.

Following the design of the study, the practicalities of applying the **method** are described. The study took place in the Illawarra and Sydney areas and accessed both providers and recipients of care, initially via Sexual Health Clinics. The negotiation of access was a prolonged and difficult process. Over time it was found that networking was a more effective way of gaining participants than using the more formal route of the Sexual Health Clinics.

The instruments for data capture were designed specifically for use in the study and were subject to pre-testing and piloting. All responses were coded and placed on computer, interviews were transcribed in full.

The final section describes the methods of **analysis**. All questionnaire data were entered into the computer using the software package, Excel 5. Several approaches were utilised as follows:

1. Determination of classes of patients, in terms of maximisation of resource use variance explained.

A distinctive feature of this study is that the episodes are deliberately defined to comprise care needs throughout the continuum of care, over a prolonged period of time. No restriction was placed upon settings of care. The classification of patients was not be rigid, movement will occur depending upon the changing social and clinical features presented as the disease progresses.

Another distinction is that only patients' needs for care were used to define the class boundaries, rather than descriptions of actual care provided.

- 2 For each care needs class, determination of sub-classes of patients, in terms of maximisation of between group variance in actual service provision.
- 3 Analysis of unmet needs.

Interview data were subject to thematic content analysis, with the key themes being identified. There was a comparison of the stated needs for care as described by recipients and the care needs as expressed by the providers.

5.1 Design Issues.

This section discusses issues relating to the context of the research and the reasons why certain methods were chosen as the means of data capture. The issues discussed include: the measurement of need, cost and the utilisation of healthcare as a basis for service planning; the research context; research participation; confidentiality and the methods for data capture.

5.1.1 The measurement of need, cost and the utilisation of healthcare as a basis for service planning.

Fuchs (1988) argues that measuring proximity to death is an accurate predictor of the future health needs of those with HIV infection. The rationale is that the highest concentration of expenditure occurs within the 3 years prior to death. Fuchs goes on to argue that proximity to death is an accurate predictor of cost. However, given the variable nature of the disease, this appears to be much too simplistic a method to be valuable over time. Mortality is an insufficient indicator of need, cost or utilisation. Healthcare expenditures associated with AIDS/HIV have been assessed primarily in three ways. Firstly, there was the approach which focused upon evaluating costs of in-patient care episodes (Andrulis et al 1987, 1992; Fahs et al 1992; Kelly, Ball & Turner 1989). The second approach included estimates of the annual costs of care (Bennett et al 1992; Hellinger, 1991, 1992), while the third method has examined lifetime costs associated with HIV/AIDS care (Hellinger, 1991, 1992, 1993; Hardy et al 1986; Scitvosky & Rice, 1987).

As managed-care approaches assume a stronger foothold in Western medicine (Markson et al 1994), analyses of the costs of one particular period and one stage of the disease spectrum offer a limited view of health care costs, utilisation and need. Extended time periods are necessary, as are estimates of the differences in patient severity of illness, in order to

discriminate between persons with HIV infection and those with AIDS, both groups having widely varying clinical courses.

It is necessary to develop analytical models which can incorporate other measures of health status provided by clinical and community studies. The development of specific indicators (and their measurement) requires the description of service utilisation. It is recognised that severity of disease and resource use are generally dependent upon utilisation information. However, individuals do not always seek care when experiencing symptoms and it is essential that the frequency of service use does not determine the individual's severity level. It is recognised that if individuals fail to seek care, then it is difficult to assess the illness severity, except from self-reporting. However, it is only those in need of care who are able to accurately describe their needs for care and perceived shortfalls of health service provision.

It is postulated that there is a need for ongoing information systems which serve evaluative, clinical and administrative purposes. Information is collected on the clients served, the services offered and the outcomes achieved. It is recognised that in the absence of design considerations such as randomised experimental and control groups, information systems are usually weak in making causal inferences. Nevertheless, they can provide valuable data on the operation of a programme, and the feedback of such information serves to make programme modifications.

An information system can serve as an important preliminary step in performance management and contribute towards strategic planning. Moreover, it is the basis upon which intermittent effectiveness evaluations can be built. An information system would furnish the data for analysis which in turn would assist in the development of analytical models.

5.1.2 Research context.

Kellehear (1993(a): 126) asks whether there is "... a correct methodological approach to health research". He develops this comment by doubting as to whether one method or a group of methods is "... consistently superior for yielding valuable insights in comparison to other methods"(1993:126). He argues that research methods should be complementary to the research questions asked, but in addition the methods employed in a study should also be "... sensitive to the needs and features of the respondents or the social processes being studied".

At the outset of the study there was the understanding, albeit an implicit one, that the main parameters of the study were twofold:

- 1 aspects relating to the author: the questions posed; time constraints; resources; ethics; politics and gender; and
- 2 aspects relating to the participants: social and personal characteristics, particularly in this instance for the HIV positive group, sexuality and states of health.

It is essential to outline these parameters, as it was recognised that the impact of the author and the participants would have no small bearing upon the study design. Mechanic (1989) argues that the researcher is the research tool and as such it is most important to calibrate "one's self in order to objectively place the research in context" (p26). Kellehear (1993:127), argues that "most methods can be learnt by any monkey" however, it is how the method is used that is the crucial issue. To be aware that the key components of the research study, that is: the researcher, the participants, and the research situation, are viewed as having equal importance, is central to this study.

The fact that the author was female, heterosexual, and not normally resident in Australia were all factors which had the potential to influence the response of the participants, who in the main would be male, homosexual and Australian. The level and amount of impact of the author's characteristics are unknown.

5.4.3 Research Participation.

At the outset of the study, it was apparent that there were two distinct groups of potential participants. That is, health care providers and HIV positive individuals. There would have to be a different approach taken to each participating group. For the clients, that is those individuals who are HIV-infected, it was the intent to study this group over a period to time, to judge changes in the disease processes and their need for health care, in response to these changes. This would require a longitudinal study. The healthcare providers would be questioned on a "one -off " basis as their views would be sought from a variety of settings throughout the duration of the study.

The context in which research takes place undoubtedly influences the response of the participants and the manner in which they respond. In the context of AIDS, Watney (1991:13) states that the

"ceaseless quest for scientifically verifiable "indicators " and "objective correlates" is pointless if they only serve further to blind social scientists to the complex realities of human life in coping with a complex spectrum of disease, which has found discourse in puritanical, moralistic and anti-gay societies".

It was recognised from the beginning that people with HIV/AIDS have been the subject of considerable research and many would be wary of participating in a study which had the potential to be intrusive. In Australia, the vast majority of individuals who have HIV/AIDS are gay men. The researcher who is not gay, male, nor HIV infected, could be perceived by some potential participants as unsympathetic to some of the problems of living with the double stigma of being gay and HIV positive. This was a recognised problem.

In the past, when dealing with marginalised individuals, according to Watney (1991: 8) "academic research still tended to treat its subjects as more or less exotic deviants, and the fluidity and complexity of sexual and drug-using behaviour were not recognised because of the rigid dependence on categories such as prostitution, homosexuality and so on". People with HIV/AIDS, regardless of their sexuality, are a marginalised group, due in no small part to the way the rest of society treats them. It was essential that participants in the study were not made to feel as though the research was some form of "voyeurism" in the manner described by Miller (1991:56), and that their views, opinions and experiences were crucial to the description of need, and use of, health care services.

Consequently, a key and underlying theme of this study was dedicated to listening to what individuals were able and willing to tell about their experiences. This approach can only derive from a truly open-minded willingness to try to describe and comprehend the situation in which so many individuals who are HIV positive find themselves. Viney and Bousfield (1991:757) in their study of narrative with AIDS- affected people noted that

"social scientists, unlike scientists in other areas, often need to take on the role of speaking for those who participate in our research, especially in relation to illness, where the voices of patients are rarely heard. We need to acknowledge the abilities they have to construct their own meanings for events and reflect upon them."

The authors, in this particular instance, were describing the results of interviews. However, the concept of enabling people to have the opportunity to express in their own words their experiences of being HIV positive, seemed directly relevant to this study. Viney and Bousfield (1991:757) went on to discuss

"the need to be respectful and representative of research participants and the need for awareness on the part of the researcher of the social and cultural values being brought to the research, so that with AIDS research we can choose to make those values humane and empowering rather than supporting the stigmatisation of those affected."

In the study of chronic disease it has usually been the narrative of medical researchers which has dominated (Williams, 1984), rather than the 'tales of those affected'. It would seem appropriate that there would be opportunity for individuals in this study to give voice to their opinions, feelings and experiences of health care.

Providers of health care work in an ever changing social and political environment. There are competing demands on resources and personnel. The ability to provide care can be facilitated or hampered by issues such as conflict of interest and competition with other service providers for limited resources. However, it was seen as essential to the study that the views of providers be sought on their abilities to provide care. In this way, the views of the need for care as expressed by both providers and recipients could be attained. The experience of the provision and receipt of health care services can be used to inform and compare the development of services. It is only by accessing both groups, that the question of how well the needs of HIV/AIDS infected individuals have been served by the healthcare system can be addressed. Valuing the views of the respondents was paramount, as it was felt that this would assist in overcoming problems of access related to gender and sexuality.

At the outset, Sexual Health clinics were chosen as the source of contact to HIV infected people as according to Silverman (1990:196) "Sexual Transmitted Disease (STD) Clinics are a significant site for identifying people who are HIV positive, staff are used to talking about sex and are used to issues relating to client confidentiality." Clinic staff were also approached as they are deemed to be key service providers for AIDS/HIV care.

The key requirement for entering the study was a willingness to participate; being HIV positive if a care recipient and having knowledge and expertise in the field of AIDS/HIV care, if a care provider. It was recognised that HIV/AIDS infected persons had been heavily researched since the start of the epidemic. Therefore, access to this group was largely determined by willingness to participate in this study. Sample size was determined by "saturation" (that is, there was concurrent data collection and analysis until there was no

new knowledge attained) and when no other individuals agreed to participate (Sarantakos, 1993: 143).

Sampling is an issue which requires discussion. Whilst the initial intent of the study had been to use a system of probability sampling, it was recognised that due to access constraints, the ability to randomly select and choose the sampling unit was unlikely. In this study for reasons of accessibility and practicality, it was realised that a non- probability sample would be the most likely result. In non-probability samples, elements are selected by non -random methods. There is no way of estimating the probability that each element has been included and there is no assurance that every element has a chance to be included.

The non-probability approach is known to be less likely to produce accurate and representative samples. Despite this fact, the vast majority of samples in most disciplines are non-probability samples (Dane,1990). In this study non-probability or convenience sampling (Agar, 1980; Morse 1990) was used, although it has elements of purposeful and nominated sampling(Field & Morse,1985; Polit & Hungler, 1987; Diers 1979; Morse 1990). Subjects are selected based upon accessibility and a known characteristic, such as being infected with HIV/AIDS or, in the case of health providers, deemed able by the nature of their work to be to have a level of expertise in the care of people with HIV/AIDS. It should be noted that the selection criteria are not mutually exclusive. It is known that there are individuals who are health care providers, are HIV/AIDS infected and in receipt of care. The criterion for study inclusion may mean that some groups of the HIV/AIDS population are excluded, due to the following factors:

- non-attendance at a Sexual Health Clinic;
- denial of HIV infection;
- seeking care/ medical attention from another source;
- not identifying as an individual who requires care for HIV/ AIDS;
- perceived barriers on the part of the individual, such as stigma, judgemental attitudes about being infected;

- refusal to participate as they feel that they are being treated as "exotic deviants" (Miller, 1990).

It is essential that the sample, despite being convenient in nature, is representative of the HIV population and the groups providing care. Therefore, it was a requirement that the majority of the HIV/AIDS sample are gay men, since this is the group most heavily affected by HIV/AIDS in Australia, however, others were not excluded.

The provider group included those individuals delivering care in a wide range of settings, for example, the community, hospital and hospice environment. This group included: doctors, nurses, general practitioners, counsellors and other health care providers working in formal and informal capacities.

5.4.4 Data Capture.

This study involved the application of pluralistic methodology. The various methodological approaches which were to be utilised were as follows:

- trend extrapolation
- economic / demographic / epidemiological analysis

The initial stages involved reviewing the literature. It was necessary to utilise the device of sub-studies, in order to maintain control over the various facets of data gathering /analysis.

The key areas addressed were as follows:

- Service quality, quantity and access as perceived by recipients and providers
- Recipient requirements which are not being addressed by current service
- Provider perceptions of current service provision
- Description of service utilisation in relation to status of disease process

Longitudinal research is employed when the investigator is interested in changes (Bulmer, 1979:11), or in the recognition of changes over time (Minichiello et al 1990:202). This method does allow for the recognition of the influence of time, specifically related to "comparisons over time as well as to precision and economy" (Sarantakos, 1990:135). There are a number of problems relating to the use of the longitudinal approach (Bailey, 1982; Stergois, 1991). Success or failure of longitudinal investigation depends on the strengths of the individual researcher to maintain contact over time, which can be an idiosyncratic process. Factors influencing the success or failure of this type of study include the following:

- retention rates -- these will be severely affected by the experience of involvement in the early stages;
- the time of recruitment and the level of information given to participants;
- attrition, mortality and migration ;
- convincing individuals to take part and remain motivated;
- completion of the questionnaire has a low priority for individuals whose health is deteriorating;
- as participants become more interested in the study, they may through interest unwittingly distort the findings;
- completion of sensitive personal data may be filled in inaccurately over time.

The self enumeration questionnaire was chosen as the method of collecting data from the HIV/AIDS group. Surveys are familiar to the general population (Sarantakos, 1993) and as such are non-confronting and non- threatening. The main characteristic of this survey method is that there is limited interference on the part of the researcher. This can be seen as being advantageous when dealing with issues of a sensitive nature, as the respondents have the power to choose whether or not to respond. The questionnaire, therefore, offers a greater degree of anonymity than an interview. The method is convenient and allows individuals to respond at a time of their choosing. There is the potential to contact and

survey larger numbers than with the interview method and the questionnaire is less expensive in terms of "man hours" than the interview, plus there is a greater potential coverage of people over a wide geographic area.

The advantages of questionnaires include: the ability to contact greater numbers; anonymity for respondents; convenience and low cost. There are limitations to using this method, as described by Sarantakos (1993) and Polit and Hungler (1987) which include:

- there is no ability on the part of the researcher to probe, prompt, nor clarify questions nor answers given;
- there is little opportunity to persuade and motivate the respondent to participate and /or respond;
- the identity of the respondent is not necessarily known, and the conditions under which the respondent answered the instrument are unknown;
- there is always the potential for questionnaires to be only partially answered, answered incorrectly, or returned unanswered.

The types of questions employed in the questionnaire were a mixture of fixed alternative and open ended questions. The mix was purposeful; using fixed alternative questions makes for an ease of completion, especially when the respondents may not be in the best of physical or mental health. The fixed alternative or closed question limits the number of possible answers and can be pre-coded so that each reply can have a specific code for the purpose of analysis (May, 1993). According to Moser & Kalton (1983:414), "the purpose of coding in surveys is to classify the answers to a question into meaningful categories, so as to bring out their essential patterns".

On the other hand, the open ended question, used in conjunction in the form of a contingency question (Sarantakos, 1993), allows for additional information of a more

specific nature to be sought, whilst allowing for the discretion and freedom of the respondents to reply (May, 1993).

A key aspect of data collection was to collect data on the psychological status of the participants at various points along the disease spectrum. Mental health is a specialised area and it was recognised that a previously utilised questionnaire would be the most appropriate way to collect data. The 28 item General Health Questionnaire (GHQ), as developed by Goldberg, was employed to measure the mental health of respondents. This scale uses general health questions to examine how people have been coping **during the past few weeks**, in comparison with the usual level of functioning. Respondents choose one point on a four point scale (**ranging from better than usual, or more than usual to much worse than usual or not at all**) to indicate their recent levels of functioning. The GHQ yields an overall measure of mental health and four sub-scales measuring: felt psychological disturbance, unhappiness, social discomfort, and lack of identity. However, it is important to note that the GHQ is a **screening** instrument for detecting independently verifiable forms of psychiatric illness and does not make clinical diagnoses. It is not suitable for the assessment of long stage (chronic) problems, as it does not detect them. The GHQ therefore records the mental state in the presence or absence of physical illness. This is a flaw as individuals who are dealing with a chronic illness will have a different perception of their physical, mental and social well-being than people who are not experiencing any form of illness (Bowling 1991). According to the authors, Goldberg and Williams (1988) it is a pure state measure, assessing present state in relation to usual state (the authors claim that this question wording is not distortive as most people see their usual state as a normal state). Bowling (1991) reports that physically ill people score highly on the GHQ, thus this group are over-represented among false positives. In order to countermand this problem Goldberg (1978), in the manual for the administration of the GHQ, points to the necessity of manipulating the threshold score to enhance discrimination in different populations. Goldberg and Williams (1988) suggest raising the thresholds for use with severe physical illness. Threshold scores are defined as equivalent to the concept of "caseness" that

corresponds to the average patient referred to psychiatrists (Bowling, 1991). If the results of the population GHQ scores are compared to independent psychiatric assessment, it is possible to state the number of symptoms where the probability that an individual will be thought to be a "case" exceeds 0.5. This is called a threshold score, the proportion of respondents above this threshold is the probable prevalence of illness.

Because of the nature of its response scale, the GHQ is likely to miss very long standing disorders, since respondents answer "same as usual" (and thus score zero) for symptoms they are experiencing and have been experiencing over a long period of time. However, Goldberg and Williams (1988) point out that the loss of cases is minimal as many people cling to a concept of their "usual self" as being symptom free.

Data on both the reliability and validity of the GHQ are reported by Goldberg (1978). Briefly, in order to study subjects with stable mental health, Goldberg (1978) selected twenty subjects assessed by him to have the same degree of disturbance at two interviews held six months apart, finding a (test-retest) reliability coefficient of .90. When 65 patients who in their opinion had not changed were interviewed, test-retest reliability was .75, while the GHQ scores for patients whose physicians identified them as stable had a reliability coefficient of .51. All patients were psychiatric attenders at local hospitals. To assess the internal consistency of test items, split-half reliability, computed on 853 completed questionnaires, was .95.

Little is known on the predictive validity of the GHQ, although Prince and Miranda (1977) found patients with high GHQ scores were more likely to be readmitted following heart surgery. Goldberg (1978) reports 11 studies that have investigated the concurrent validity of the GHQ 30-item and 60-item instrument scores either against the Clinical Interview Schedule (Goldberg, Cooper, Eastwood, Kedward & Shepard, 1970), the Present State Examination (Wing, Cooper & Sartorius, 1974) or interviews with experienced clinicians. Correlations with clinical assessment range between +0.70 and +0.88, while sensitivity and

specificity estimates ranged from 70% to 91% and 73% to 94%, respectively. Goldberg and Hillier (1979) report 88.0% sensitivity and 84.2% specificity for the 28-item GHQ and the Clinical Interview Schedule. Thus it can be concluded that the GHQ has moderate reliability and concurrent validity. Although the GHQ was not developed as a predictive tool, Goldberg and Williams (1988) report that those with the highest GHQ scores have been reported to have the highest use of health care services. Berwick et al (1987) provided further evidence of the predictive validity of the GHQ; elevation of GHQ scores, over two administrations at seven month intervals, were strongly associated with the probability of both mental health and non-mental health healthcare, being sought and used, within twelve months. As a screening instrument Bowling (1991) states that the GHQ is sensitive to transient disorders detecting symptoms of at least two weeks duration. It is according to Bowling (1991) sensitive to depression disorders and detects anxiety as well, so it is suitable for use when a broader measure is sought. Despite claims by Goldberg and Williams (1988) that the GHQ is a measure of mental health status it would appear that mental health cannot be judged in isolation from the physical health of an individual. The observation by Bowling (1991) that people with physical ill-health score more highly on the GHQ relates not only to the perception of the individuals but also to the wording and design of the GHQ. Despite these problems this instrument is easily understood, is written in everyday language and was used as part of the 1989 General Household survey, and as such may hold a vague degree of familiarity for some respondents. The use of the GHQ in this study is to screen and give an indication of the levels of, and changes in mental health, at the same time acknowledging the changing physical status of the individuals in the study population.

The interview approach was chosen to elicit information from the health care providers, as it was felt that they were more likely to respond to the personal approach. They as a group would have less cause to be anxious about being identified, and would possibly be more willing to cooperate in an interview setting. As the author has had extensive experience in health care, she was of the opinion that if individuals agreed to be interviewed, they would generally comply. A questionnaire, on the other hand, would be lost in the 'mass of

paperwork'. It was envisaged that this group would be small in number and relatively well contained geographically.

The interview approach was chosen as verbal methods, such as interviews, have "an ability to reach into all content areas" (Webb et al 1966:181) and the semi-structured approach allows for flexibility to further probe and formulate questions as required (Sarantakos, 1993). In effect, the interviews were focused as the respondents were asked to discuss the research questions providing their views and opinions (Sarantakos, 1993; Minichiello et al, 1990). This approach was chosen as it focuses upon the research topic and aims towards maximisation of the potential of the study. It allows the discussion to go beyond the initial themes and encourages the respondents to discuss as many of the issues surrounding and impacting on the topic as possible (Dane, 1994; Polit & Hungler 1987; Sarantakos, 1993). Minichiello et al (1990:92) commented that "semi-structured interviews or focussed interviews are modelled on the unstructured model of interviewing. This means that the topic area guides the questions asked, but the mode of asking follows the unstructured process." This form of in-depth interviewing allows for an extensive examination of individuals and the topic. It was argued (Minichiello et al 1990) that the style may reduce comparability of interviews within the study, but it does provide for a more "valid explication of the informant's perception of reality"(p92). Although appearing free flowing there was a minimal level of control, whereby the interviewer kept the informant "relating experiences and attitudes that are relevant to the problem" (Burgess 1982:107).

Both the interview and the questionnaire are methods of obtaining self-reported behaviour and according to Kellehear (1993(b):5) "one of the major sources of error in questionnaires and interviews is believing what respondents say they do or do not believe." For this reason the data collection was repeated with a variety of groups to test for and ensure consistency. The reliability of the instruments, with the exception of the GHQ, was unknown. However, the responses by participants were deemed to be credible and authentic. There was a considerable degree of trust on both the part of the researcher and

the participants that the data were 'true' and there was the implicit understanding that they would be dealt with honorably. Truth is an emotive word and an arbitrary term due to the fact that what is true in one instance may not be true in another. Dean & Whyte (1958) suggest that researchers have no cast iron guarantee of the truth of what they are being told. All they can be sure of is that they are being told something about the individual's subjective state at that time.

It was recognised that the self reporting nature of the data could be problematic. There was the concern that individuals would not have sufficient knowledge about their clinical status. Therefore, if further access to medical records was denied, then it would not be possible to append key clinical detail. However, it was noted from the literature that persons with HIV are perhaps not as unknowing about their treatment as the wider population. This is reinforced by Patton (1990:54) who stated that "it doesn't seem at all unusual to most gay men that their hairdresser or a man picked up in a bar knows as much about AIDS medicine as many doctors."

The amount of information on internet regarding treatment options, particularly in the **sci.med.aids.** group is indicative of the thirst for knowledge about the disease within this group. Also, support and activist groups such as ACON and Act-Up have played a prominent role in the provision of information about treatment options, and in the lobbying of governments about the availability of drugs.

5.4.5 Confidentiality.

Confidentiality is central as an issue to this study both in terms of gaining access to the study population and in maintaining data confidentiality. Confidentiality is an acknowledged duty of health professionals (Gillon, 1986; Siegler, 1982; Rumbold, 1993). It has foundations in ethics and has some legal force. Allmark (1995) suggests that there is

a more disingenuous reason for citing it as a duty: that it helps a group attain professional status.

In western society there are a number of practices which are publicly condemned and privately enjoyed by a fairly large number of people. Among these is the use of recreational drugs other than tobacco and alcohol, prostitution and same gender sex. Whilst only those that are illegal lead, of necessity, to corruption and crime, all lead to secrecy. HIV infection is intertwined with this secrecy in a way unlike almost any other illness (Allmark 1995:158).

Certain features about HIV infection conspire to make this so. These are as follows:

- HIV can be hidden. There are no tell-tale signs until it has developed into AIDS.
- HIV can remain hidden for many years.
- HIV is infectious but not hugely so. However, the mechanism by which it is spread, means that it tends to be linked to practices that are identified as being publicly condemned and privately practiced and, as such, to secrecy.
- HIV infection cannot be eliminated from the body, nor cured, and is associated with the terminal syndrome of AIDS.

The interrelation of features means that the health professional has privileged access to two pieces of information about which the person with HIV is likely to desire confidentiality: lifestyle and the fact of a positive diagnosis. For participants in this study, the idea of secrecy is intertwined with the notion of seeking care from a Sexual Health Clinic (SHC). There they are able to feel assured that their confidentiality will not be compromised. This is due in no small part to the reputation of these sites for the maintenance of confidentiality and anonymity.

By stressing their need for confidentiality, the SHCs (and needle exchange sites) in order to operate, make themselves vulnerable to a double-edged argument. That is, confidentiality is part of their *raison d'etre*, but the costs of confidentiality outweigh any benefits (Gillett,

1990), therefore the clinics should not exist (Allmark, 1995). They are vulnerable to general anti-consequentialist arguments as put forward by Bok (1984), which suggest that confidentiality should be in the interests of the client or society. Bok (1984) noted that a claim by a profession or group of professionals that they needed confidentiality in order to fulfill their functions is always going to be a source of conflict. For, if society comes to perceive that the negative effects of that profession's duty of confidentiality outweigh the positive, then the existence of the profession will be called into question. Certainly the profession would be able to say that their *raison d'être* required confidentiality. But people might say that their operations legitimate harmful practices, in this case unsafe sex and that society would be better off without them. Therefore, individuals could be sacrificed for the public good. To the extent that these clinic services rely on the cost benefit morality of consequentialism that, according to Allmark (1995), means that "breaches of confidentiality are justified to maximize happiness"(p163), so shall they be judged. However, if people start to count the cost in terms of, for example, avoidable cases of infected spouses and children, then the services may come under threat.

It was seen as imperative to reassure all study participants that confidentiality was assured. Names of individuals and clinic sites were not needed, nor to be divulged to any other source. Individuals could choose a pseudonym or code, which would be placed upon their questionnaire in order that, over the period of study, continuity of their responses could be tracked over time. Confidentiality, in the sense of anonymity, was also enhanced by the use of postal questionnaires that did not require the meeting of researcher and respondent. No subsidiary information would be sought without the expressed permission of participants. It was recognized that the feeling of being the "gate-keepers" of privileged information would have a bearing upon whether SHC staff and others would allow access to individuals with HIV infection.

In order to maintain data confidentiality, all sources of raw data were kept under lock and key, were not be accessible to any other, and all responses were coded. Clinic or surgery

names were not be available in any written form. In that way it was not possible to identify sources. However, some areas were happy to be named. In entering data onto computer, raw data was transcribed onto paper in its coded form, this was essential as the office space was shared and the risk of material being "left lying around" and being inadvertently viewed by others was too great. Confidentiality was acknowledged as a potential problem. Subsequently, practical measures were designed into the study to ensure the maintenance of trust, which is the essence of the confidential relationship.

5.5 STUDY METHOD.

The method chosen was a longitudinal study which by design created a database. Longitudinal research is characterized by the fact that it employs a procedure whereby the respondents of the original group are studied on more than one occasion (Sarantakos, 1993). In this instance, as well as the original group, others were also included and hence the study might be known as a trend study (Sarantakos, 1993).

Data management was enhanced by the maintenance of a longitudinal database. The list, in Appendix 1, describes the data elements that were collected and maintained on the database. Its design involved the examination of existing databases including the AIDS register and hospital and service delivery records; recent and planned developments in data management including the infectious disease database (IDDS) and the national minimum data set for hospitals; the AIDS Oral History Project and proposed developments specific to AIDS/HIV. In this manner data triangulation (Dane 1990; Polit & Hungler, 1987) was possible. Data had the potential to be cross checked. For example, if the code on the questionnaire was annotated by clinic staff then the individual code could be traced on the AIDS Register (the same code is used) and thus the data could be cross-checked. Also, if an individual gave permission for their medical record to be examined, then it was possible to append clinical data for which they had poor recall, and data could be cross checked. The database had a

relatively simple structure at the general level. There was a record for each person, which was created at initial contact.

Initial contact was defined as self selection of a patient from those attending a collaborating health care delivery unit or those individuals who through networking volunteered to participate in the study. Patients in the test database therefore included new cases arising during the study and others attending for care at varying intervals after their initial diagnosis. For the latter group, some of the historical information was reconstructed from recollection. Basic socio-demographic and clinical data were appended at this stage. Additional information was then added after each contact with the health care delivery system that occurred during the study period.

Contacts included attendance for health care at the initiative of the patient. They also included contacts initiated by the investigator for the purpose of pursuing research goals specific to the project.

In order to comply with ethical requirements, a protocol of the study was submitted to the relevant bodies for approval, prior to commencement. Ethical approval was granted by the Ethics Committee of the University of Wollongong. Ethical considerations can be summarized under three areas: general considerations, confidentiality and risk to subjects.

(a) General Considerations

All respondents were given a standardized introductory letter asking them to participate and briefly out-lining the level of commitment. There was no deception, no invasive techniques and limited contact. The initial intent was that subjects would only be known to the researcher by a code. However, it emerged that some disclosed their names. No record of these names was retained and these respondents were also coded in the same manner as all the other respondents. For those who returned a consent form allowing access to their medical records, this was noted by way of an additional code (the letter C) being appended to their computer listing.

(b) Confidentiality

All respondents were informed that the study was confidential and that they would only be known to the researcher by a code. All coded responses were kept in a locked filing cabinet. Questionnaire and consent forms would be incinerated at the end of the study once raw data had been checked and entered onto the computer.

Respondents were informed that no individual would be identified either directly or indirectly by demographic description. Respondents were assured that all questionnaires would be destroyed upon study completion. Interview transcripts were retained, but they held no other identifier other than an indication of the occupation of the respondent. For example, N1 stood for nurse number 1.

(c) Risk to subjects

There was no risk to subjects as there was no intervention which they had to undertake as part of the study. The study was descriptive and as such did not impose any intervention or activity upon the subject.

5.6 STUDY PARTICIPANTS

There were two distinct groups of participants: those in receipt of healthcare and the providers. For ease of presentation these will be outlined separately beginning with the recipients of healthcare -people with HIV/AIDS.

5.6.1 The recipients of healthcare--People with HIV/AIDS

For those in receipt of healthcare, the sole condition for them to participate was that they were diagnosed as persons who are HIV infected, at varying stages on the time scale from being newly diagnosed as having HIV, through to development of AIDS. The key factor was that they would agree to participate in the study. There was no coercion as the researcher did not have the initial contact. Individuals were approached by staff in Sexual Health Clinics (SHCs).

It was envisaged that the majority of the respondents would be homosexual males, as this is the most severely affected group in Australia. Potential respondents were to be approached by SHC staff and asked to participate. However, as the study progressed individuals approached the researcher and volunteered. They had heard about the study from others. These individuals were included in the study as they fulfilled the two main criteria for participation: they wished to take part and they were HIV positive.

The method was piloted in the Illawarra area and later extended to the Sydney. At this point, the informal networking of study participants and the researcher proved to be invaluable way of recruiting participants. Although SHC sites were approached, very few replied even to initial inquiries about study participation. Anecdotal reasons for this include: the sites have been and continue to be bombarded with study requests; staff in an effort to protect clients are declining invitations to participate in studies; and letters and telephone call messages simply "got lost" in the system. However, the success of networking from the pilot encouraged proceeding along this fashion. This was a good decision reinforced as several participants commented that although they attend clinic X, they had never been approached about the study.

Of the clinic sites approached, two agreed to participate, on the condition that the clinics would not be identified. In reality, a very small percentage of the total participants was

recruited through a clinic, the majority were recruited by networking by other participants and the researcher. Informal contact with groups such as Living Positive, Body Positive, Anakali and the Community Service network, proved to be an excellent means of recruitment. In effect it did not limit the study to a description of services provided through the auspices of the SHC network.

The method, therefore, used the concepts of purposeful sampling (Agar, 1980; Field & Morse, 1985; Morse, 1990; Sarantakos, 1993), nominated sampling (Diers, 1979; Field & Morse 1985) and snowball sampling (Sarantakos, 1993). These methods were employed due to the problems of gaining formal access, and hence it was difficult to approach the respondents in any other way.

5.6.2 Healthcare Providers.

The opinions and views of professional staff were also sought regarding the type and level of services currently provided. Staff was approached through the SHC system, informal networking and direct approaches in the case of general practitioners (GPs). As the study progressed, it became apparent that a significant amount of care was being given by informal carers and some were included in the interview component.

The respondents by the very nature of their work were deemed to be able to provide useful and relevant information on the topics being investigated and were regarded by others to have a level of expertise in the field of HIV/AIDS care. The method therefore used purposeful sampling (Agar, 1980; Field & Morse 1985; Morse, 1990) and nominated sampling (Diers, 1979; Field & Morse, 1985). The size of the sample was dependent upon when "saturation" of the data was reached, or when no more individuals agreed to participate (Sarantakos, 1993:143).

5.7 The data collection instruments and their construction.

Data gathering required the development of specific tools, involving survey and interview schedules (Appendix 2). For ease of presentation the instruments will be described separately starting with the questionnaire, which was the tool chosen for the client (HIV positive) group.

5.7.1 The Client Questionnaire.

In relation to the client (HIV positive) group, the survey instrument was a mailed questionnaire, whilst for clinic and other professional staff, the instrument was an interview schedule. The instruments were designed specifically for use in this study, with the exception of the second part of the client questionnaire, the "General Health Questionnaire" (GHQ) which was designed by Goldberg et al (1978).

Structure of the Questionnaire.

The questionnaire was comprised of three main elements, each having a certain purpose: the cover letter, the instructions/consent form and the main body. These will be described separately for ease of presentation.

The construction of the instrument starts with the statement of its conceptual aims moves on to through its application, to the results. The process is a combination of inductive and deductive techniques (May 1993). The questionnaire was subjected to systematic construction, being reconsidered and discussed with colleagues. This invariably led to the conclusion that the questionnaire needed further modification. It took several re-drafts prior to the "finished product" that was deemed ready for pre-testing.

The pre-test was undertaken with ex-colleagues and friends in London, all of whom were either HIV positive, or working in the field, or both. The pre-test revealed that there was a need for changes, primarily in the sequence of questions but also in the wording of questions, with some being deleted, others added.

The Cover Letter.

The cover letter served to introduce the respondents to the nature of the research. By adequately describing the purpose and giving reassurances about anonymity, it was hoped that it served not only as an introduction, but also as a way by which doubts and concerns about the study could be alleviated. It is hoped that it also served to encourage respondents to participate in the study. The cover letter was on the headed note- paper of the University Department in which the researcher was studying, to legitimate the source of the questionnaire. The letter offered assurances on the confidentiality of respondents' identity and their responses. Instructions on the return of the questionnaire, using an enclosed stamped addressed envelope, were also included in the letter.

Instructions/Consent Form.

Instructions on how to complete the questionnaire were part of the main body of the instrument. Instructions on how to contact the author to request further information and how to return the questionnaire were included in the cover letter. A consent form was also included for return, if the respondent would be willing to allow the researcher to access their medical records, or to access via another information that would be contained in the same.

The Questionnaire.

The main body of the research instrument was the questionnaire and the format was as follows:

- Part 1** contained questions relating to the following:
the HIV status of the individual, access to treatment/care; drug use; use of healthcare and voluntary services
- Part 2** General Health Questionnaire
- Part 3** Personal details such as age, sexual orientation, other peoples' knowledge of their HIV status and so forth.

The types of questions employed in Parts 1 & 3 of the questionnaire were a mixture of fixed alternative and open ended questions.

Finally, there were two blank pages left with the sole purpose of inviting individuals to make comments and express opinions about their experiences of living with the HIV virus. This was included in order to obtain information from the viewpoint of the respondents, by allowing them the space to "tell their own tales".

The General Health Questionnaire

The 28 item GHQ, as developed by Goldberg, was employed to measure the mental health of respondents. This scale uses general health questions to examine how people have been coping **during the past few weeks**, in comparison with the usual level of functioning. Respondents choose one point on a four point scale (**ranging from better than usual, or more than usual to much worse than usual or not at all**) to indicate their recent levels of functioning. The GHQ yields an overall measure of mental health and four sub-scales measuring: felt psychological disturbance, unhappiness, social discomfort, and lack of identity.

5:7:2 **The Interview Schedule.**

Data were collected from providers of health care by means of a semi-structured interview. An interview schedule was developed (appendix 3) to elicit information and the opinions of key service providers concerning the following:

- 1 their individual role and the role of the clinic overall;
- 2 the health and social needs of people with HIV/AIDS and the extent to which these are met by current service provision;
- 3 the co-ordination of services for people with HIV /AIDS.

Staff were contacted and asked to participate in the study. No-one refused. There had been a considerable period of time involved in negotiation with key staff members to gain access to the study areas, particularly for the pilot study. This negotiation of access involved initially writing to the Sexual Health Clinic Director, explaining the purpose of the study and seeking their assistance and participation in the study. The letter was then followed up by a personal telephone call, and time arranged to discuss the study with the Director and /or all the staff. At this stage, the staff were assured that they would not be identified nor would their tapes be available to any other person. Individuals were also informed that they did not have to participate-it was entirely voluntary. At the time of interview they could request that the interview not be taped, taping being used solely for the purpose of accuracy of reporting. It was also made clear that the sites where individuals were employed would not be identified without the permission of the respondents. Thus to ensure and promote confidentiality, assurances about the levels of confidentiality were made explicit as were reassurances about anonymity.

It is important to note that not all respondents in this group were contacted through a SHC. The majority of respondents in the main study including: community nurses, GPs and voluntary carers were approached directly after being recommended, through networking

with individuals and community organizations. These people were contacted either directly by telephone, or else they were asked by another, to contact the researcher. The same reassurances about confidentiality and anonymity were given.

It was seen as important that the interviewer maintained a calm, friendly demeanor. After all people were willing to give information for which they could not see an immediate personal gain. Although the place where interviews occur can have an impact upon the interview process (Sarantakos, 1993; Polit & Hungler, 1987; Minichiello et al 1990), there was no control over this particular aspect, and the interviews took place at a time and place convenient to the respondents.

5.8 Method of analysis.

There are several approaches that were utilized in the study. The simplest approach, however, may be summarised as follows:

- 1 Determination of classes of patients, in terms of maximisation of resource use variance explained.

The idea is to define a small number of classes of episodes in terms of patient characteristics, such that members of the same class are similar in terms of the expected total costs of meeting patient care.

A distinctive feature of this study is that the episodes are deliberately defined to comprise care needs throughout the continuum of care, over a prolonged period of time. No restriction was placed upon settings of care. The classification of patients was not be rigid, movement occurs depending upon the changing social and clinical features, presented as the disease progresses.

Another distinction is that only patients' needs for care were to be used to define the class boundaries, rather than descriptions of actual care provided.

- 2 For each care needs class, determination of sub-classes of patients, in terms of maximisation of between group variance in actual service provision.

The same idea is applied, excepting that the sub-classes are defined to maximise the variance explained in terms of actual costs of care. Simply stated, the resultant classification identifies classes of patients in terms of their needs, and sub-classes of each in terms of the services they actually received.

- 3 Analysis of unmet needs.

For each sub-class, there is a statement of needs (the class value) and a statement of services received (which is unique to this sub-class). The difference between these values is a description of unmet needs.

This last main step focuses on analysis of these differences. The main aim is to identify strategies for addressing unmet needs. However, there is also the possibility that some persons are receiving services which are currently very expensive and could be provided in another form: for example, inpatient stays could be substituted for other forms of care, if available. This kind of outcome is most likely to result from comparisons across sub-classes within the same care needs class.

All questionnaire data were placed upon data input sheets and checked for validity and reliability by one other, prior to being entered into the computer. All statistical analyses were computed using the Excel version 5, or by hand. Unless otherwise stated, for statistical purposes, an alpha level of $p < .05$ was utilised as evidence of a significant result, with three other levels of significance ($p < .01$; $p < .005$; $p < .001$) determined **a priori**.

Trend analysis was included (alpha level of .10; as evidence of significance) because of the small number of subjects per intervention, and because of the relative importance of Type I versus Type II errors in an area where no previous research has been conducted.

For the interview component, all interviews were transcribed verbatim as recommended by DeVault (1990). Thematic analysis of data was undertaken, with codes being derived from the data itself rather than being predetermined. Data analysis was largely descriptive, the purpose being to categorise and order the information in such a way as to make sense of it (Brink, 1990) and to identify emerging themes (Polit & Hungler, 1985). The coding of the content of a random selection of the transcripts were checked by one other independent coder, in order to arrive at the areas categorised for discussion, thus increasing the reliability and validity of the analysis (Brink, 1990; May, 1990). Due to the informal approach taken the responses tended to be of a discursive nature. The text was broken down into meaning units of single and multiple sentences and then categorised. The areas of irrelevant information in an interview described by Field and Morse (1985) as "dross" were deleted from the overall content analysis. The interviews were categorised and analysed using the word processor and the package of Word for the Macintosh in a manner similar to that described by Burnard (1993).

5.9 Conclusion.

From the literature it is noted that although writers make a case for longitudinal research there is little literature which addresses the practicalities involved in attempting to undertake such work. The practicalities of studying a group who have been heavily researched and in some instances, protected from researchers by others, was a key consideration of this study. In many ways the complex arena in which this work was conducted demonstrated that the context in which the research takes place, is an environment in which extraneous social pressures can influence the participation, behaviour and response of the participants and the

researcher. Yet the benefits of being able to address and describe changes over time were deemed too valuable to bypass.

The methods of data capture whilst they have inherent problems are appropriate to the type of study being undertaken. The use of purposive and convenience sampling were in essence a reflection of the necessity for compromise in order to capture data on such complex groups. As noted by Seed (1995:845) when conducting a longitudinal study "it became apparent that the "idealized" canons of research as described in the literature are not necessarily translatable or indeed useful in practice". Finch (1984) points out that if researchers sanitize their writing, purging them of their real experiences and concerns, then the literature will fail to represent "how" research is actually done. In many ways the need to access participants and to maintain confidentiality determined the conduct of the study.

Chapter 6: The Pilot Study.

Overview.

This section describes the findings from the prospective pilot study. Whilst it is uncommon to report the findings of the pilot in full it was deemed essential to do so in order to ascertain whether the pilot had been successful in gaining the type of information sought. It was important to test whether or not it was possible to gather meaningful data given the possible constraints of confidentiality and other barriers. It is important to note that the HIV infected participants from the pilot study were "carried over" to be part of the main study. The aim was to gather both qualitative and quantitative data on the needs of people with HIV/AIDS and to ascertain whether current health services are meeting these needs. The view and opinions of both staff and clients were sought.

The study had two main components:

- an interview with care providers;
- and
- a client questionnaire which was completed each time care was sought.

The findings which include the following will be described:

- demographic details of the client group;
- clinical aspects of the HIV infection- treatments used, symptoms experienced;
- opinions of staff and clients regarding the services currently available;
- the costs of care;
- the use of DRG classes to cost care.

Issues of note that arose from this study are:

- confidentiality is of paramount importance when dealing with a group whose data by their very nature are sensitive. Respect for the privacy of individuals is a key issue;
- the use of Diagnosis Related Groups is not static, individuals constantly move from one group to another depending upon their symptoms;
- co-ordination of care is an issue central to both clients and staff;
- Access to care is a central issue;
- Individuals in this pilot sought care from multiple sites often based upon personal networking, this was a factor for both recipients and providers of care;
- Due to the complexities of care sought and provided, the costs of hospital and community care are difficult to discern.

The pilot study was prospective and formed part of the larger study. The pilot was used to ascertain whether the method could be used to track individuals over time and to plot changes. The pilot was successful in demonstrating that the study method and data collection instruments could be used to track changes over time. Individuals from the pilot study formed part of the large study.

6:1 Study Design.

The study was of prospective design. The aim was to gather both quantitative and qualitative data on the needs of people with HIV/AIDS. In order to estimate whether current health services are meeting these needs, the views of both clients and key service providers were sought. The setting for data collection was Sexual Health Clinics.

A small pre-test using 10 individuals (in London UK), who were attending a non-NHS care centre, was conducted to test the questionnaire. Following the pre-test, the ordering of some questions were changed and a question regarding alternative treatments was included. The wording of some questions was also changed to assist the overall completion of the questionnaire. The section containing the General Health Questionnaire was placed in the middle of the survey document, as respondents felt that this made it feel "less like an after thought". The survey information sheet was also changed, with explanations and instructions being made more succinct and explicit (appendix 2 contains the pilot instrument).

For ease of presentation, the data and procedure for each part of the study: that is, the response to interviews by staff and the data captured by questionnaire from the recipients of care, will be described independently, commencing with the staff interviews.

6:2 : The Interviews of Service Providers.

6:2 (a) Data Collection: the Interview Schedule.

A semi-structured interview schedule was developed to elicit information and the opinions of key service providers concerning:

1. their individual role and the role of the clinic overall;

2. the health and social needs of people with HIV/AIDS and the extent to which these are met by current service provision;

3. the co-ordination of services for people with HIV/AIDS.

6:2 (b) The Sample.

The interview sample consisted of all staff currently employed at the Sexual Health Clinic, Port Kembla. The Clinic was staffed by 2 doctors, 2 nurses, 1 social worker and a receptionist. The respondents, by the very nature of their work, were deemed to be able to provide useful and relevant information on the topics being investigated. They are regarded by other health-care workers in the area to have a level of expertise in the field of HIV/AIDS care. The method therefore utilised the concepts of both purposeful sampling (Agar, 1980, Field and Morse 1985, Morse, 1980) and nominated sampling (Diers, 1979, Field and Morse, 1985).

6:2 (c): Method of data capture.

Staff were contacted and asked to participate in the study. No-one refused. After obtaining verbal consent, tape-recorded interviews were undertaken. Interviews lasted between 35 minutes and 3 hours, the average length being 1 hour and 5 minutes.

6:3 Data Analysis of the Interviews

All interviews were transcribed in full. Data analysis was largely descriptive, the purpose being to categorise and order the information in such a way as to make sense of it (Brink, 1990) and to identify emerging themes (Polit and Hungler 1978). The coding of the content of a random selection of the transcripts was checked, by one other independent coder, in order to arrive at the areas categorised for discussion, thus increasing the reliability and

validity of the analysis (Brink 1990, May 1990). The discussion following is the product covering the main themes which occurred in the pilot interviews, and which were identified by the aforementioned process.

6:4 Interview Findings.

All respondents interviewed had direct care, co-ordination and teaching components in their role. The respondents considered themselves to hold specialist knowledge in the field of HIV/AIDS care, either by virtue of some form of special training and/or the experience of working in the field for some time.

Opinions on the value of specialisation of services for people with HIV/AIDS varied considerably, often reflecting the varied philosophies of their individual disciplines and backgrounds. A key theme which emerged concerned the use of generic services. People with HIV/AIDS were considered to be of low priority in comparison with other groups of clients. It was expressed that this may be due to actual (few) numbers of clients. It was a general and repeated theme that generic health-care workers were inadequately trained and sometimes unwilling to meet the needs of people with HIV/AIDS, in addition to their already burgeoning caseloads.

Service Users.

All respondents commented that they expected the client group proportions to change over time. Although the clients being seen were still almost exclusively white, middle class, gay men, it was known that there were women, people from ethnic groups, IDUs and heterosexual men who were HIV positive in the local community. However, as yet they were not choosing to attend the clinic for treatment. These trends whilst not yet occurring can be expected in the light of the changing pattern of the HIV epidemic.

In terms of health status, the clients currently attending the clinic covered a broad range of dependencies and presented with a wide spectrum of infection and disease. One respondent commented that the dependency of current clients was increasing. The majority of clients tended not to have been diagnosed locally and were in the middle stages of infection. The increasing dependency of clients was partly attributable to the increased longevity associated with HIV/AIDS, resulting in people developing more disabling infections and living longer with their sequelae.

Services provided: overlaps and gaps.

It appears that some services including: information and referral, psychological support, welfare rights and housing advice are being provided by a plethora of organisations (19 different community groups and organisations were mentioned during the course of these interviews). Conversely, acute medical and nursing care, residential care, convalescence, rehabilitation, dental and terminal care are provided by a small number of organisations chiefly: ACON, Anakali and the health service.

In relation specifically to home care services, practical help, psychological support, personal care and/or befriending services to people with HIV/AIDS in the community, this role is largely governed by the Anakali network and the other networks (for example, the Community Service network) which fall under the auspices of ACON. The private sector services were reluctant to undertake such work. It was the majority opinion that these organisations did not have the skills and knowledge to equip them to deal with people with HIV/AIDS.

However, it should be recognised that these data are opinion based and do not give any indication of actual quality or quantity of service by any organisation. Furthermore, the fact that some services are only provided by a small number of organisations does not necessarily represent an overall gap in provision. The data here need to be complemented

by information on the need for particular services and the extent to which these needs are met. Clinic staff were therefore asked to consider:

(a) gaps in service or unmet clients needs

(b) areas of overlap in services provision.

Gaps in service or unmet clients needs.

The gap most commonly identified were psychiatric services, particularly community based. These were reported to be severely lacking for people with HIV/AIDS, who were experiencing mental health problems. It was noted that psychiatric staff were currently overburdened, unaware of the specific problems that people with HIV/AIDS faced and were unable, due to lack of time and expertise, to become involved. As one member of staff stated:

"Getting psychiatric support in the community is very difficult. People are already busy and I think they may be afraid of taking on a whole new client group. But, there certainly is a need, ranging from people with emotional problems right through to major dementia."

When asked about overlaps in service provision, all respondents stated that similar situations existed but in a different geographical area.

Service duplication was thought to be most common in the area of psychological support, advice work, referral and practical /social support. One respondent did comment that this sometimes led to over-provision of services to individuals and hence to client confusion. All respondents did feel that despite the potential for overlap, there appears to be a need for a concerted approach and greater availability, in a short waiting time, for help of this type. It was stated that by individual staff members networking with voluntary and statutory

organisations, this type of overlap was consciously avoided at the level of individual clients. However, it was felt that some degree (levels not specified) of service duplication was justified to ensure client choice.

Minority Groups.

The second most commonly identified area of unmet need was in relation to minority groups affected by HIV and AIDS. This is particularly relevant in the Illawarra area, as there is a large and diverse ethnic mix. It was felt that cultural and language barriers existed which inhibited and prevented some persons of ethnic minority background admitting and seeking help for "at risk" behaviours.

Women of a non- English speaking background (NESB) were of particular concern, especially those who were working in the sex industry. It was known to staff that there were some women who were working in the local area, who due to their NESB and immigration status (they did not have legal residence status), were unable to access care. They were those least likely, in the opinion of staff, to be in a position to ensure that they practised safe sex. These women were thought to be very vulnerable, as were their clients.

Housing and Financial Benefits

There appears to be a lack of specially adapted housing, sheltered or supported, for those who are disabled or highly dependent. Housing services are inundated with demand and the current waiting time is two years, even on the priority list. It was commented that people with HIV/ AIDS are being apparently ranked with other vulnerable groups, with the result that only those who were seriously ill were given a high priority.

Similar limitations affected the provision of financial support, another area of unmet need according to respondents. The system for claiming statutory benefits and allowances was

considered to be slow and complex. People who are HIV positive, but not unwell, faced similar problems to people who were ill, but they did not meet the criteria for some benefits and allowances. Finally, it was the general consensus that the income offered to people who were ill and unable to work was woefully inadequate to meet their needs.

Residential Care

A further major area of under provision was apparently that of residential care in a non-hospital setting. This applied to two different groups of individuals: those requiring long-term care and those who needed short term respite /convalescence/rehabilitation /terminal care. This service is only available in the Sydney area. There was overwhelming agreement that this kind of service needed to be available in the Illawarra area and should be an urgent priority, as demonstrated by the following comment by a staff member:

"It's encouraging that people with HIV are living longer, but this means we are seeing people who are more dependent - they may be blind or unable to walk or be demented. This puts extra strain on the carers. Both the clients and the carers need to have a break - so there is really a need for residential care, but it shouldn't be hospital most don't need or want that."

Gaps in Community Services

There was a general consensus among respondents that it was desirable for people with HIV/AIDS to be cared for in their own homes. However, many felt that there were major gaps in the provision of community services, particularly when intensive support, or continuous 24-hour supervision was needed. It was also stated that some community nurses and general practitioners frequently lacked the knowledge and skills, and were some times unwilling to provide care to people with HIV/AIDS.

People with HIV/AIDS often required practical assistance, such as help with shopping, cooking, cleaning, and so on. In this respect, statutory support services were reported to be extremely inadequate and voluntary agencies were depended upon greatly to provide this kind of assistance.

The respondents were united in the opinion that as numbers of people who are HIV positive and increasingly dependent increase, there will inevitably be a greater reliance on informal care. Two respondents were emphatic in their opinion that:

"Traditional family networks may not be available to all client groups. For example, some gay men, IDUs and refugees, and for those persons who do have informal carers, the demands placed upon them are potentially enormous."

All the respondents were of the opinion that the need for respite care and support services for informal carers would grow in the near future.

Referral to other healthcare services.

The problem of referral to health services within the locality was touched upon. It was inferred that there were difficulties in referring patients, due to a fear on behalf of the patient that more individuals would be made aware of their HIV status. As one member of staff said:

"This is a small town and although much is done to protect privacy, simply by being seen attending the clinic here and one of the local hospitals can raise fears. People fear being seen and subsequently, having to explain or cover up, what they were doing."

Individual members of staff were often in a quandary about the referral of clients to other agencies /health specialities. They feared a breach in confidentiality and questioned the

ability of staff in other specialities to understand the complexities of HIV care. Even in referral to specialist centres, there was an air of confusion, as there seemed to be a plethora of individuals who claimed specialist knowledge about the virus. As commented upon by one staff member:

"Everyone from virologists to immunologists try to stake a special claim on clients with HIV. Then there are the chest physicians who hold court over people with PCP, the hospice staff for the terminally ill and not forgetting the specialists in HIV medicine. I end up referring to people I know and trust. Their label is often less important than their ability to access care for the individual. To me, the most important thing is that the patient receives timely and appropriate care that they feel comfortable with. Medical and hospital power politics be damned!"

From the comments made it seems as though referral and subsequent accessing of care is not as straight forward as it might be. There appear to be the barriers of knowing who to refer to, coupled with the fear held by clients that their privacy may be breached, albeit unwittingly.

What are the needs of people with HIV/AIDS, and are these needs unique to people with HIV/AIDS?

All but two of the respondents felt that the needs of people with HIV/AIDS were mostly or often the same as the needs of other people with chronic illnesses, such as cancer. This is illustrated by the following comment:

"I don't think there is any difference between a person with HIV or AIDS, or anyone else, who's got an ongoing chronic illness."

However, the remaining two respondents felt that drawing parallels with people with other chronic illnesses was actually unhelpful or irrelevant. For example:

"The needs are very different, but I think there is a tendency to want see HIV as 'just another chronic illness' and it is not."

Factors influencing the needs of people with HIV/AIDS.

A number of factors were thought to influence the needs of people with HIV/AIDS and to differentiate between HIV/AIDS and other chronic illnesses. Stigma was the commonly mentioned factor by all respondents. There is a great deal of evidence indicating that the stigma associated with HIV/AIDS results in prejudice, ostracism, harassment and oppression; all of which were reported as common problems by respondents in this study.

Four of the respondents considered the fact that most people with HIV/AIDS are facing a life-threatening and potentially disabling disease at an early age was another unique factor. This not only made acceptance of help problematic, since those affected are usually not used to being in a dependent role.

AIDS is a relatively new disease surrounded by uncertainty. New treatments are continually being tested and new claims being publicised. This uncertainty and inundation with information was felt to add to the stress faced by those confronting the infection.

All the respondents thought the modes of transmission of HIV through sex and injecting drug use added to the stigma associated with the illness. Furthermore, HIV brings to the fore a whole range of issues, which are linked with social taboos in Western society, including sex, particularly homosexual sex, drug abuse, racial discrimination and death.

Common needs of people with HIV/AIDS

There was agreement amongst respondents on the common needs of people with HIV and AIDS. Those identified include:

- access to continuous counselling and psychological support at various stages throughout the illness, including psychiatric services where necessary;
- participation in decision making;
- non-discriminatory, supportive attitudes and care from all professional and non-professional service providers;
- strict policies and assurances of confidentiality;
- advice and advocacy in relation to welfare rights;
- easy access to a range of social support services;
- special, locally based residential facilities (not hospitals) for use at particular times during the illness;
- appropriate housing
- easy access to practical assistance with domestic and other practical tasks, for example, cooking, shopping, and so on.
- specific dietary advice and access to appropriate meals services/ help with cooking;
- intensive community support when ill, including 24 hour cover for highly dependent clients;

- services specifically for informal carers.

There was agreement that all services should offer a rapid response and be flexible.

Service Coordination.

People with HIV/AIDS use a broad range of services, which stated one respondent:

"These people need a whole variety of services but they need them instantly not when some clerk or somebody else thinks they are needed. It is essential that there is some form of co-ordination so that services meet the needs of these people."

Respondents in this study generally felt that co-ordination was poor. Every respondent made some criticism of service co-ordination. Typical comments included:

"Co-ordination is very poor. It's very informal, the linking at the moment. It depends on the individual dealing with the case. There is no structure to the current way I liaise with other agencies, it's all who you know, so I would say that it is a big area of weakness."

"Co-ordination.....it's a joke ...there is no co-ordination."

"There are a number of forums, but there are so many you could spend your working life attending them also, everyone has their own axe to grind and often little is achieved."

To an extent, these fora were seen to be successful in forging links between service providers and for the exchange of information and views.

Most service co-ordination appeared to take place informally and at individual client level. However, case conferences, involving all those involved in providing care for a single client, was rare. The setting up of such meetings was fraught with logistical difficulties and confusion.

Problems of co-ordination appeared to be particularly acute between the clinic services and the various agencies providing community care. Some of these problems appeared to stem from the fact that many clients 'shopped' around for their medical care and treatment, but also were in receipt of community care on a local basis. Occasionally this caused misunderstandings between the various agencies. The fact of clinic staff having to liaise with a large number of community workers, across a wide area, was felt to hamper good co-ordination.

Territorial Attitudes.

A further barrier to service co-ordination was the reported "territorial" attitudes of certain organisations and individuals, who were apparently reluctant to refer clients on to others for help. There was a tendency to try to cater for all needs through one service.

There was some evidence of antagonism between clinic staff and certain other agencies. From the comments received this may have been due, in part, to poor understanding of the roles, skills and abilities of other personnel from both parties. Attitudes were felt to hinder co-ordination of care and could have the potential to limit client's access to care.

Summary

The increasing spread of HIV and the level of demand this will place on services, occurs in the context of service quality, appropriateness and effective resource use being scrutinised

by health service planners. The results of this small pilot study indicate the broad range of needs experienced by people with HIV/AIDS and highlights some of the shortcomings of current services, as perceived by those working in one particular area. The illustrated problems associated with the co-ordination of services must have an impact upon the eventual quality of service received by the clients. Albeit that these were the opinions of a small number of people working in one specialised area, the opinions are valid, given that they reflect the environment in which the individuals are delivering care. Their views would have merit in the future development of HIV/AIDS care in the Illawarra area, particularly if the views of need are reflected in the views of service recipients.

It is recognised that these data are reflective of the work and opinions of a small group of individuals working in a specialised area and as such are biased. How far these views will be ratified will become apparent with future study.

Subsequent stages of data collection enabled further interpretation of the data. However, it does seem apparent that individuals are working in an area where the necessary co-ordination of services is hampered by a lack of time and the possible reluctance of other agencies to become involved. This was not stated explicitly but was inferred in the comments. This factor alone will have an impact upon the quantity and quality of services offered.

The areas of unmet need identified, relate not only to the specific health care needs, but also to the social care needs. Barriers to care access were identified as being both professional and social, illustrated by difficulties in referral to other care sites and social barriers, such as ethnicity.

6:5: Self -Enumeration Questionnaire for AIDS/HIV Patients.

This was a three part questionnaire covering the following areas:

- (i) service needs and uses
- (ii) Goldberg Health questionnaire
- (iii) personal details.

Most of the questions were multiple choice, people only having to encircle or tick the most appropriate response. The fixed alternative approach was chosen, with follow-up open ended questions being used to elicit further information. A summary of the variables under investigation are as follows:

Demographic: ethnicity, age, sexuality, occupation, marital status, living arrangements;

Clinical: general mental health (GHQ), drug use, health services used;

HIV status: time since diagnosis, current and previous symptoms.

The Sample.

Participants were drawn from those persons attending the Sexual Health Clinic at Port Kembla. The profile of those attending who are HIV positive has changed marginally in the past five years. Initially the client group comprised solely of gay men in the late stages of HIV infection, who had returned to their home area to die. However, the profile of those requiring care has changed. The client group remains predominantly gay males, but now tends to be those who are “long-term” survivors. In April 1993, there were 94 persons in the area who were registered as being HIV positive. (Figure courtesy of ACON, Wollongong.)

On average, the clinic sees twelve to fifteen HIV positive persons per month. An outreach “rural “ service also operates, which serves the Shoalhaven area. The number of persons who are HIV positive, who attend this service, fluctuates from none to five persons. It is important to be aware that according to clinic staff, those HIV positive persons seeking care through the auspices of the Sexual Health Clinic are not representative of all persons who are HIV infected in the Illawarra area. Due to the proximity of Sydney, many persons choose to seek care there.

Participants were those persons who agreed to participate. They were initially approached by clinic staff and asked if they would be willing to take part in the study. However, during data collection an unusual phenomenon occurred, the researcher was approached by other persons who had heard about the study by “word of mouth”. These persons were living in the area, were HIV positive and were gay men, but rather than attend the Sexual Health Clinic, they attended their family doctor for all aspects of their health care. This group were included in the data collection, as it was considered that they would be able to provide useful and relevant information on the topics being investigated.

A total of forty (40) participants volunteered and responded in the pilot study, all completed the follow-up questionnaire, giving a compliance rate of 100%. The method therefore utilised the concepts of both purposeful sampling (Agar 1980, Field & Morse 1985, Morse 1990) and nominated sampling (Diers 1979, Field & Morse 1985).

Method of Data Capture

A pack containing an introductory letter, the questionnaires and a pre- addressed envelope were left at the clinic, clinic staff actually asked individuals to respond. The process by which clinic staff selected potential participants, was determined by factors beyond the control of the researcher. Among others, these included not wanting to "bother" clients they

believed were too ill. Those who were more physically or mentally impaired, were less likely to be asked to participate in the study.

In order to identify individuals a code was entered by clinic staff on the top of the questionnaire, and in a log, held and kept by clinic staff. Follow-up questionnaires were sent some 4-6 months after the initial questionnaire; these were distributed by clinic staff, coded by them and again came complete with a pre-addressed stamped envelope to facilitate return.

Those persons who had entered the study by “word of mouth” were given the pack. In addition it contained the follow-up questionnaire and the second pre addressed envelope. This group were asked to return the second questionnaire, following their next medical appointment for their routine screening, or in six months time which ever came first.

6:6 RESULTS.

All data from the pilot study were entered into a database using the software package Excel 4. Individuals are not identified, except by a number. The link between the number and the individual is known only to the author and is not kept in any written format. As the study expanded did the database and individuals from the pilot will continued to be followed at six monthly intervals in order to enhance the quality of longitudinal data available. Due to the coding employed it was possible to verify data using the AIDS register, provided the name given to the author is the same as has been given to the clinic staff.

Demographic Characteristics of the Sample.

All members of the sample were male (100%, n=40) and all were HIV positive. The mean age of the respondents was 36.3 years (range 16-53 years). Figure 1 following graphs the age distribution of the participants.

Figure 6:1

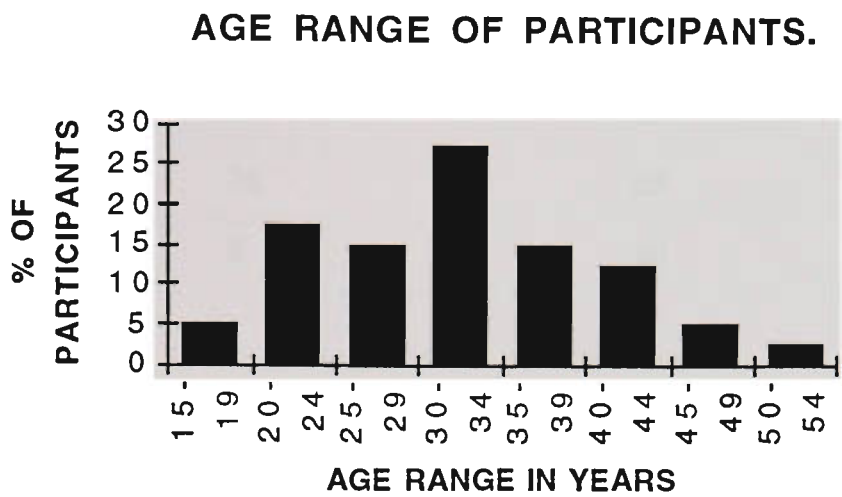


Table 6.1 (following) encapsulates the demographic characteristics of the participants. The majority of respondents (65%) described themselves as single, 7.5% as married, 15% as divorced, 7.5% as separated and the final 5% were in a “de facto” relationship. The question related being in a relationship to a woman.

In terms of sexual orientation, 65% of respondents identified themselves as homosexual, 15% were heterosexual and 20% bisexual. Interestingly, 18% of respondents stated that whilst they were predominantly homosexual, they also stated that they were heterosexual, they were firm in their conviction that they were not bisexual. This is in conflict with the literature on self-described sexual orientation where nine out of ten men will identify themselves as gay or homosexual (Ridge, Plummer & Minichiello, 1994 :321) This may be due to the fact that most studies have recruited individuals from specific sites where the probability of identifying as gay would be high.

Table 6:1Demographic characteristics

<u>Marital Status</u>	<u>Number</u>	<u>Percentage (%)</u>
Single	26	65.0
Divorced	6	15.0
Separated	3	7.5
Married	3	7.5
"De-Facto"	2	5.0

Table 6:1 (continued)

Sexual Orientation

Heterosexual	6	15
Homosexual	26	65
Bisexual	8	20

Race

Aboriginal	2	5.0
Asian	1	2.5
Caucasian	35	87.5
Maori/Polynesian	2	5.0

Occupation

Unemployed	8	20.0
Professional	23	57.5
Non -Professional	6	15.0
Student	3	7.5

Residence

Urban	29	72.5
Rural	11	27.5

Co-habitation Status

Alone	11	27.5
Parents/ Family	1	2.5
Husband/ Wife	3	7.5
With Lover	15	37.5
With Friends	4	10.0
In a Shared Residence	6	15.0

The majority of respondents were Caucasian, 87.5%, 5% Aboriginal, 5% Maori / Polynesian and the remaining 2.5% Asian.

In terms of the residence and living status of participants, it is interesting to note that 27.5% of respondents live alone. This group cover all ages and stages of the disease. It is postulated that this group could place greater demands on the health and social services as their disease progresses. Living alone was associated with being a professional worker. Living alone was also associated with having a private physician and increased attendance at a clinic or doctor’s surgery. Individuals with a private doctor visited them more often than those individuals whose usual source of medical assistance was the Sexual Health Clinic.

In terms of occupation, people were divided into four categories: unemployed, (20%) professional, (57.5%) non-professional, (15%) and students, (7.5%). The majority (57.5%) of respondents were in the professional category (see table 6.1). It is of note that only 15% of respondents were now no longer working, this excludes those who stated that they were unemployed. This group exclusively incorporates those individuals who have an AIDS diagnosis.

Knowledge of HIV status by others, was not significant amongst any of the groups. Table 6.2 reveals the spread of other individuals who know the HIV status of the respondents.

Table 6:2 Knowledge of HIV Status

Those Who Know	Number	Percentage (%)
No-one	6	15.0
Lover Only	10	25.0
Parents Only	1	2.5
Husband / Wife	3	7.5
Family & Close Friends	13	32.5
All Personal Contacts	7	17.5
Totals	40	100

There was a direct correlation with time since diagnosis (>24 months) and family and close friends being aware of the diagnosis ($r=0.89$). There were no other results of note.

Broadly speaking, the respondents were middle-class white, gay men, and as such they are representative of the HIV/AIDS population in the Illawarra region. It is acknowledged that the sample is biased, but is one which was convenient and responsive to participation in the study. One individual agreed to participate "in the hope that it might benefit others with this wretched disease". This response would seem to indicate that there may be a degree of altruism associated with study participation but given this was only verbalised by one respondent, at this stage it is conjecture on the part of the author.

6:6:2 CLINICAL CHARACTERISTICS OF THE SAMPLE.

6:6:2(a) THE RESULTS FROM THE MENTAL HEALTH QUESTIONNAIRE.

Using the 28-item GHQ (Goldberg Mental Health Questionnaire) and scoring GHQ method (0-0-1-1), the mean mental health for this sample was at baseline ($n=40$) 2.8 (SD= 4.1; range 0-16.). Using the recommended threshold score 4/5 (Goldberg, 1978), 14 of 40 (40%) had evidence of poorer mental health, 6 scoring 12 or above. Table 6.3, following, describes the results.

Table 6:3 Frequency of Total Mental Health Scores on the 28-Item General Health Questionnaire

GHQ Score	Baseline		Follow-up (6months)	
	Number	/ Percent (%)	Number	/ Percent (%)
High (12-28)	6	15.0	6	15.0
Mid range (5-11)	8	20.0	12	30.0
Low (0-4)	26	65.0	22	55.0

A series of 2 x 3 Chi-squares analyses to investigate whether any of the group (baseline, follow-up) reported a greater frequency of poorer health, at any particular stage during their disease, were undertaken. There was no statistically significant result. It is recognised that this may due to the small sample size and the associated problems with using Chi-squared on a small sample.

It was noted that there was a direct correlation between experiencing symptoms and a high GHQ score ($r=1$, $p<0.05$). It was found that all persons who had been diagnosed for 6 months or less and for more than 24 months were experiencing symptoms and reported high GHQ levels . Table 6.4 describes the frequency of scores for the four key areas of the GHQ. It can be seen from this table (6.4), that the majority of respondents were placed in the low categories, and as such did not report levels of change of mental health that would cause concern. This may be due to the fact that most individuals had adapted to living with HIV in its symptom-free state. It was notable that upon experiencing physical symptoms, individuals reported a change in their perception of their general feeling of well-being.

Table 6:4 Frequency of scores on the 28 -Item General Health Questionnaire.

	<u>Baseline</u>		<u>Follow-up</u>	
	Number	Percent (%)	Number	Percent (%)
Somatic Symptoms				
HIGH (3-7)	6	15.0	8	20.0
(2)	4	10.0	7	17.5
Low (0-1)	30	75.0	25	62.5
Anxiety & Insommnia				
HIGH (3-7)	5	12.5	6	15.0
(2)	7	17.5	7	17.5
Low (0-1)	28	70.0	27	67.5
Social Dysfunction				
HIGH (3-7)	8	20.0	9	22.5
(2)	6	15.0	8	20.0
Low (0-1)	26	65.0	23	57.5
Severe Depression				
HIGH (3-7)	4	10.0	6	15.0
(2)	1	2.5	4	10.0
Low (0-1)	35	87.5	30	75.0

The odds ratio indicated that persons in the following time frames since diagnosis, 6 months and less and 24 months and more, were 5.2 times more likely to score highly on the GHQ.

DRUG USE AND REPORTED SYMPTOMS.

This section deals with prescribed drugs and non-prescribed drugs which people reported using. In the management of HIV, it is recommended that the CD4 count is monitored every 3-6 months and when the cell count drops below 500 anti-HIV treatment is given. These treatments are also given when the CD4 count is at 500, if the individual is experiencing symptoms. At a level less than 200, prophylaxis is given for opportunistic infection or in the case of experiencing symptoms when the CD4 count is greater than 200, but less than 500. The drug of choice is the anti-retroviral drug zivodine, commonly known as AZT. It is known that AZT has severe side effects, particularly in people who are severely immunosuppressed. It is for this reason that AZT is commenced when an individual is well, on a low dose, in order to minimise side effects.

Other anti-retroviral drugs include dideoxyinosine (ddI) and dideoxycytidine (ddC). In this study four respondents were on ddI, all went to a GP for care; the majority (30) were on AZT and six respondents did not report being on AZT or any other anti-retroviral. Interestingly, all six respondents had been diagnosed as HIV positive for more than 2 years. It is unknown whether they chose not to take AZT or whether clinically they were unable to do so.

Other medication was in direct relation to symptoms experienced. During the course of the pilot, 19% of the HIV positive men were without symptoms, the rest all experienced symptoms on a constant (reportedly daily) basis.

The main symptoms experienced by the respondents were as follows:

weight loss, malaise, thrush, shingles, headaches, peripheral neuropathy, herpes (genital and widespread), chest infections, low platelet count, Kaposi's Sarcoma, pancreatitis, encephalitis, septicaemia, cytomegalovirus, pneumocystis carinii pneumonia (PCP); cryptosporidium infection of the bowel, diarrhoea; fatigue; mouth ulcers.

As can be seen by the list the respondents were party to a full range of opportunistic infections. Table 6.5 details the drugs taken in relation to each of the opportunistic diseases. As can be noted from this table although there are a wide range of drugs employed, this list is not exhaustive, for example, the drug therapy for encephalitis is not detailed as it was not outlined by the individual.

Table 6:5 Reported Drug use in relation to treatment of Opportunistic Infections

<u>Infection</u>	<u>Reported Drug Use</u>
Candidias (Thrush)	Topical: Nystatin, Amphotericin B lozenges Systemic: Fluconazole, Ketoconazole
Cytomegalovirus (CMV)	Gancyclovir (DHPG), Foscarnet
Cryptosporidium Diarrhoea	Codeine; Lomotil;
Herpes (Simplex& Varicella Zoster)	Acyclovir
Kaposi's Sarcoma (KS)	Chemotherapy,
Mycobacteria Avium (Fever)	Paracetamol plus those listed below for MS
Mycobacteria Septicaemia (MS)	Rifabutin, Clofamazine, Isonazid, Ethambutol
Pneumocystis Carinii Pneumonia (PCP)	Dapsone, Co-trimoxazole, fandisar, Bactrim; Cortisteriods especially cortisol, Pentamidine

It is also recognised that some of the symptoms experienced could be a direct result of the level of drug therapy being used to treat particular symptoms. It is known that some of the

medications are given as prophylaxis. For example, dapone and bactrim are given as prophylactics for PCP when the individual's CD4 count drops below 200.

The majority of respondents (87.5%) took vitamin supplements. All stipulated that they obtained them from ACON (40%) and/ or purchased them themselves.

There was no apparent pattern with symptoms experienced and time since diagnosis. There was one exception. There was a direct correlation with having Kaposi's sarcoma and having been diagnosed more than 24 months. This can be explained in part by the fact that this study uses time since diagnosis which could be different to the time of sero-conversion. All twelve individuals with Kaposi's sarcoma had had chemotherapy within the last six months.

There was no significant difference between the drug regimens employed by the SHC and GPs. Length of time on drug therapy ranged from 2 weeks through to 6 years. Length of time was directly correlated with the time since diagnosis, particularly in relation to therapy with AZT.

It is of importance to note that although prescribed, drugs may not be taken by the respondents. Nine individuals commented that they had been prescribed drugs, but were not currently consuming them. Reasons for non consumption of prescribed drugs were unknown.

HEALTHCARE USE.

Fourteen of the respondents stated that their key source of medical help was their General Practitioner (G.P). The remainder (26) sought their care from a Sexual Health Clinic (SHC). It is notable that these twenty-six persons tended to use the SHC for care which they perceived as being HIV/AIDS related. The level and assumptions on which the decisions were made as to which source of care to approach are not known. It is important

to note that the respondents who used a SHC as their main source of care, also reported using at least one other source of medical care. The respondents who used their GP as their usual care source, also reported using other sources of medical care (accident and emergency departments and 24 hour medical clinics). The absolute rate of medical care use averaged 12 GP/SHC visits in a six month period, this approximates to 24 visits per annum.

Reporting symptoms correlated with having a high frequency (more than 5 visits in 14 days) of visitation to a GP. Interestingly, this was only the case for those persons who used a general practitioner /private physician as their main source of medical help. Persons with the same level of symptom intensity, but who used the clinic were less frequent attenders. This may be due to accessibility, but reasons for this are currently unknown.

Being unemployed was associated with a more frequent use of hospital, clinic and GP facilities. This may be explained by the fact that the majority of those persons who are employed reported fewer symptoms and therefore perceive themselves to be in better health. It is recognised that simply being able to continue working does seem to indicate less health problems. However, it is acknowledged that individuals may have been unemployed prior to their diagnosis of being HIV infected. Overall, patients with a private physician reported more visits to same, (4 times greater) than those whose main source of medical care was the Sexual Health Clinic.

From the data available, it was not possible to discern the number of day cases, as opposed to specialist visits. It is recognised that this is a flaw in the data collection process in the pilot and within the current data held in patient records.

Increasing symptom intensity, as demonstrated by developing symptoms since the previous visit, increased the frequency of visits to a medical practitioner. Those persons whose usual source of medical help was their GP / private physician, had significantly more outpatient

(specialist) visits than those persons whose usual source of medical care was the Sexual Health Clinic ($p<0.05$).

Time since diagnosis was a strong predictor of clinic and GP use. Eighteen months and more since diagnosis, meant that those individuals used SHC and GP services more frequently ($p<0.01$). Those persons who were clinically defined as having AIDS reported the most visits to the doctor or clinic ($p<0.05$).

Living alone and professional status were also associated with an increased number of visits to a medical care site. There was no level of significance between using a private physician and attendance at the Sexual Health Clinic for this group.

Inpatient admissions were, as expected, strongly related to reported symptoms and/or new symptoms. Between the two questionnaires, an increase or the appearance of new symptoms increased the odds of a hospital admission (O R= 1.5). People with an AIDS diagnosis were three (3) times more likely to be hospitalised than those without an AIDS label. This is not surprising given the increasing likelihood of greater frailty and increasing complexity of the disease for those persons with AIDS.

Interestingly, individuals reported not seeking medical assistance each time they had experienced symptoms. This was significant ($P<0.05$) for those individuals whose main source of medical care was the SHC, a possible explanation of this factor could be explained as accessibility to the medical care site.

Home nursing services were utilised by 65% of all respondents, the length of time ranged from 1 day through to 23 days; suffering from PCP and /or severe multiple infection was significantly associated with use of the home nursing service ($P<0.05$).

The community mental health team was used significantly ($P<0.01$) more often, by people whose main source of medical help was their GP, than those persons who used the SHC. This can be explained by the presence of a counsellor at the SHC, 90% of respondents who attended the SHC made use of the counsellor, which possibly abated their need for other sources of psychological support. Living alone was directly associated with use of the community mental team ($r=0.9$).

Time since diagnosis, less than 6 months and more than 24 months, was directly correlated ($r=0.84$) with use of the community mental health team. It is confirmed, through anecdotal evidence gleaned through discussion with the SHC counsellor that people in these two groups visited her more frequently than other individuals.

There were no other significant results.

ALTERNATIVE THERAPIES

The majority (80%) of individuals reported using some form of alternative therapy. The most commonly named were as described in table 6.6 following:

Table 6.6 The source of Alternative therapy used in the pilot study.

<u>Therapy/Source</u>	<u>Number of Respondents.</u>
Accunpuncture	9
Chinese herbal medicine	12
Naturopath	17
Aromatherapy	26
Massage (Swedish & Shiatsu)	28

Other therapies mentioned included Reiki, use of crystals, meditation and yoga. It is recognised that some of these practices are not necessarily viewed as being therapeutic, but

rather they are life style choices. The amount and severity of the symptoms experienced by an individual, was significant in the use of massage as an alternative therapy ($P < 0.05$). Time since diagnosis was not a significant factor.

Use of an alternative therapy was not exclusive, respondents used a combination approach. There was no difference in use regardless of site of bio-medical care. However, there was a greater likelihood that the individual would be employed. This is not surprising given the cost of the alternative therapies.

There were no other significant results.

Distribution of Cases by AN-DRGs.

For ease of comparison the subjects in this study were assigned to the AN-DRG (v2) classification. The detailed definitions of principal diagnosis and principal procedure included in each of the DRGs were provided by reference to the definitions manual on DRGs (1992).

The table (6.7) following shows the distribution of HIV/AIDS cases by DRG for 1990/91, as described by Palmer et al (1991), as compared with the distribution of cases in the pilot sample.

Table 6:7 Distribution of HIV/ AIDS Cases by AN-DRG: The Sample Compared to NSW 1990/91 Figures.

<u>DRG</u>	<u>Pilot</u>		<u>NSW*</u>	
	No of Cases	Percent (%)	No of Cases	Percent (%)
801	1	2.5	127	4.4
802	12	30.0	240	8.3
803	11	27.5	1659	57.4
804	4	10.0	491	17.0
806	6	15.0	338	11.7
807	3	7.5	////	////
810	1	2.5	////	////
811	1	2.5	////	////
812	1	2.5	////	////
Totals	40	100	2889	100

* as per Palmer et al (1993) utilising 1990/91 figures.

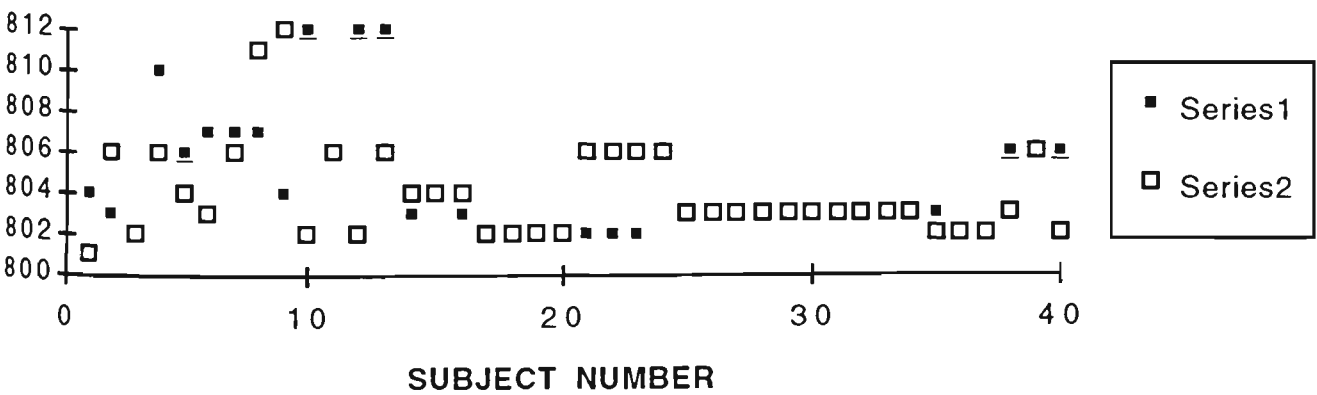
It is notable, firstly, that the paediatric groups have not been included in the table as there are no paediatric cases in the pilot sample. Secondly, in this sample there are additional DRG groups. This may be due to the fact that this is a prospective study and therefore, the classification of the individual will change over time as the disease progresses. In most DRG classifications the segregation of the episodes for the individual are carried out retrospectively and hence an individual is assigned to a group on principal and secondary diagnosis. It is argued in this case that individuals will over time change from group to group, as their secondary diagnosis changes, and therefore the case-mix and the intensity will be constantly fluctuating. This is demonstrated by an individual who is assigned to DRG 807 *operating theatre procedure for infectious disease* then, in a short space of time is re-assigned to DRG 810 *post-operative infection* . The principal diagnosis of HIV/AIDS, remains unchanged but the secondary diagnosis/episode changes. The acute episode

necessitates the change in DRG grouping with time. It is apparent that the pattern of distribution through the DRG groupings is largely similar in the pilot study to the pattern exhibited to the NSW pattern. Variations can be accounted for by differences in classifications.

DRG 802, *HIVrelated malignancy, age>9* and DRG 803, *HIV related infection, age>9* accounts for the majority of pilot study respondents. The variation from the NSW figures could be explained by: differences in classification; the fact that this pilot reflects a small number many of whom have been diagnosed for longer than 2 years (this accounts for 75% of the DRG 802 in the pilot study). In DRG 802, the principal diagnosis was *Karposi sarcoma*, whilst in DRG 803 *pneumocytosis* was the most frequent diagnosis. DRG 806 was those persons in the later stages of the disease, the change from the initial through to the follow-up can be accounted by those persons who developed differing conditions in the later stages of the disease. The principal diagnosis for most of the patients in this DRG is either *AIDS unspecified or HIV unspecified*. The figure following demonstrates the movement through the through the DRG groups, from the initial contact and the follow-up.

Figure 6:2

THE PATTERN OF DISTRIBUTION THROUGH THE DRG GROUPINGS BY INDIVIDUALS OVER THE PILOT STUDY



Start of study. Series 2= 6 months later.

It is apparent that in the 6 month period people did not remain within a single category. In Figure 2 the movement over time demonstrates the increase in severity of symptoms as individuals graduate into the categories of 802 *HIV Related Malignancy* ; which in the main encapsulates those people with Kaposi's Sarcoma and DRG 806 *HIV without specified Related condition, age>9* . DRG 806 seems to cover two distinct groups of individuals, those in the early stage of the disease spectrum and those in the terminal stages. The change from the initial categorisation to the follow-up can be accounted for by the those persons who developed differing conditions in the later stages of the disease. It is envisioned that this will affect the actual costs of treatment over time.

LENGTH OF STAY

It must be stipulated at the outset that the respondents attended a variety of hospitals in the Illawarra and the Sydney areas. There is significant variation in the length of stay across the DRGs, with DRG 801 having the longest length of stay of 24 days (1 patient), with DRG 807 having the shortest length of stay of 1.3 days. DRG 807 encompassed people who were undergoing dental work at St Vincent's Hospital, this group all had a longer stay than one day and hence could not be considered as "day only" cases.

Table 6.8 HIV-DRG Average Length of Stay (ALOS) (in days).

<u>DRG</u>	<u>ALOS-Initial</u>	<u>ALOS Follow-up</u>
801	0	24
802	9.8	6.2
803	10.2	8.6
804	6.2	5.2
806	8.4	4.1
807	0	1.3
810	0	7.3
811	2.5	5.5

Day cases were not included in these figures.

Due to the small number, the average length of stay by DRG will be skewed by an individual's results and therefore, these figures are indicative of a general trend rather than being specific.

The difference between the initial group and the follow-up group can be explained by individual cases. For example, DRG 801 had an average length of stay of 24 days, this was due entirely to an individual who had encephalitis, which necessitated a long in-patient stay. Other reasons for variation can be accounted for by the different hospitals attended, the difference in coding and different treatment protocols employed.

DAY ONLY CASES

There were 59 episodes of reported "day only" cases in the pilot study.

The DRG with the highest proportion of day only cases was DRG 803, *HIV related infection, age > 9* which accounted for 90% of reported day cases. The other 10% of cases were spread throughout the various DRG classes. The main sites for care were diverse and were as follows:

Shoalhaven Hospital, Wollongong Campus, Royal Prince Alfred Hospital, Albion Street Clinic, St Vincent's Hospital, Taylor Square Clinic, Prince Henry Hospital, St George's Hospital.

These are the day only cases and do not take into account the specialist visits. Information on this particular area was a weak part of the data collected in the pilot study. There was difficulty in verifying whether a case was truly a day only case or whether it was really a visit to a specialist for further consultation. It was not possible to verify data, as the author had no knowledge as to the identity of the GPs, in order to elicit further information. It would also be essential for participants to have given consent to access records at any site.

Individuals were reluctant to give consent for two reasons: they feared a loss of confidentiality; the name that they used in the study was not necessarily the one by which they were known at their doctor/ clinic site.

INPATIENT DRG COSTS.

The costs relate only to the inpatient stay and are based upon the DRG costs estimated by Palmer et al (1990/1). During the pilot study, there were a total of 36 inpatient episodes. An interesting feature of these episodes is that at the initial data collection stage, there were fewer episodes with a shorter average length of stay, compared to the follow-up, when the number of in patient stays had increased as had the length of stay. This is a pattern which was monitored during the main study.

The following costs are recognised as being indicative of a trend, rather than absolutes. It was hoped that more complete and effective means of costing will emerge during the course of study. Obtaining figures from the various sources proved to be time consuming and a non-productive exercise, and hence the recourse to the figures produced by Palmer et al (1993).

In the Palmer et al (1993:24) study, it was noted that "the average cost per discharge in the seven teaching hospitals was \$ 3214". The authors recognised that this figure would not remain constant; they postulated that there would be a number of reasons for change in the costs as follows:

- an increase in the size of funds available;
- a change in the number of total discharges over the period.

Palmer and colleagues (1993), based on the average cost per discharge, calculated a price per HIV/DRG, using HIV/DRG cost weights. They calculated that if a cost weight of 1.00 has a price of \$3214, then HIV/DRGs would have the following prices:

DRG 801 <i>Related Central Nervous System Disease</i>	\$6910
802 <i>HIV Related Malignancy</i>	\$5560
803 <i>HIV Related Infection</i>	\$4339
804 <i>HIV with other Related Condition</i>	\$3053
806 <i>HIV without Specified Related Condition</i>	\$2764

Palmer et al (1993:24)

The DRG with the largest number of episodes in this pilot was DRG 802 *HIV related malignancy*. There were a total of 14 episodes in this category. DRG 801 accounted for only one episode of 14 days. It is recognised that this would be classed as an outlier, but given the small number of cases in this sample it is included in table 6.9 following; which demonstrates the general costs of in-patient care utilising the cost weights as described by Palmer et al (1993).

Table 6:9: Cost of Inpatient care using HIV /DRG cost weights as per Palmer et al (1993).

<u>DRG</u>	<u>No of Cases</u>	<u>Price per HIV/DRGTotal (\$)</u>	
801	1	6910	6910
802	11	5560	61,160
803	12	4339	47, 729
804	4	3053	12, 212
806	10	2764	27, 640
Totals	<u>38</u>	<u>15,5651*</u>	

* this figure is only the costs for the final groupings at the end of the pilot study, the movement through the DRG categories already described means that the costs will fluctuate. Hence the cost is only indicative of trend.

CLINIC, DAY ONLY AND SPECIALIST VISITS -THE COSTS

It proved to be immensely difficult to obtain figures relating to ambulatory costs. This is in part due to the diverse number of sites from which individuals in this study receive care.

The cost of community nursing services for both general care and mental health are also difficult to discern as the costs are involved and complex in their construction. For example the costs of community care would have to incorporate such items as : the costs of specialist nursing care, travelling time on behalf of the community nurse, supply costs, time spent per visit and the levels of complexity of care involved, that is the activities undertaken at each site by a particular grade of nurse would also have to be incorporated. It is recognised that this is a significant cost involved, particularly in relation to DRG 806 which includes those individuals who have an AIDS diagnosis and are in need of palliative care in their home, which is an increasing trend. In order to estimate community care costs fully there would have to be an incorporation of: GP costs, community nursing care costs, the cost of specialist home care nurse, such as the palliative care nurse, and for other services such as physiotherapy and the cost of equipment used. Due to the complexity of data required it would not be possible to discern actual costs, but it should be possible to demonstrate a trend towards cost expenditure in the area of HIV/AIDS, through a description of services being utilised by people with HIV/AIDS.

THE USE OF VOLUNTARY SERVICES.

All the respondents had used some form of voluntary service in the six month period. The main source was the Community Service Network, which provides both "hands -on" support and a telephone help line. The range of time was from 1 day through 42 days. In this pilot study there was a direct correlation ($r=0.8$; $p<0.05$) between living alone and use of the Community Service Network (CSN), during times of symptom exacerbation. No other group exhibited such continuous use of the CSN, for a period greater than 2 days, as did those who lived alone.

Meals-on wheels was the second most frequently named organisation, with 40% of respondents stating that they had used their services at some point in the six month period. The range of time was from 3 days through to 61 days (and still ongoing).

The community transport system was utilised by 18% of respondents, exclusively for transport to GP, SHC and hospital appointments.

Living alone and having an AIDS diagnosis were both significant factors in the use of voluntary services ($p < 0.05$). It is recognised that this result could have significance for future use of voluntary services as 27% of respondents in the pilot lived alone.

There were no other significant results.

SERVICE NEEDS.

The respondents were asked what they perceived as the current shortfalls in the services provided. There was a unanimous response in regard to the need for the provision of the following:

- a dedicated counselling (24 hour) service staffed by trained counsellors and psychologists.
- provision of weekend and evening medical services which have specialist knowledge of HIV needs.

The need for increased public awareness of HIV and “how you catch it” was mentioned by 65% of respondents.

It was interesting to note that some 80% of respondents mentioned the need for increased medical and nurse education, but interestingly this did not relate to the staff of the SHC. Respondents made it very clear that they were satisfied with the care and attention that they

received from their usual source of medical help, whether that be the SHC or their GP, or a combination. They were dissatisfied with the levels of acceptance and general care which they received in the hospital system. The comments following serve to illustrate this point:

"The staff are always so busy at the outpatient department. I am never given the opportunity to discuss my care with them . The doctor treats the virus not me I always feel really miserable after being there ...it's just their whole approach. Maybe that's how they treat everyone, but I always feel it's because I have HIV" (32 years old, lives alone).

"He's (the doctor) fascinated by the virus, wish he was as interested in me. I notice that he never removes his gloves even when he shakes my hand at the end of the consultation. Makes me feel like a leper." (43 years old, lives alone).

These comments have significant implications for the future provision of services in the Illawarra Area, which is where these comments were directed by the individuals. There was not the same level of antipathy towards the outpatient and inpatient care which was given in Sydney. This is probably due to the numbers of patients and the greater experience of departments in Sydney.

It is notable that the respondents whose main source of medical care was the SHC had nothing but praise for the staff and the time which they gave to the clients. A typical comment is as follows:

"It's a place of safety, the staff are always warm and available to listen. They make me feel human again not just another case. To them I'm a person with complex feelings and fears, not just a host for a virus " (22 years, lives with lover).

The need for appropriate housing and adequate financial benefits were also mentioned by 55% of the respondents. As one respondent said:

"There are days when I know I should give up work, but the range of benefits are simply insufficient for me, they don't allow me to maintain my current home and the trauma of moving is a stress that I can do without." (38 years, lives alone).

In the main these opinions support the comments and opinions of the staff at the SHC regarding the needs of people with HIV.

6:7 DISCUSSION

This pilot study attempted to gather data on individuals at varying stages along the HIV/AIDS continuum, and to investigate their needs for and use of healthcare and other caring services.

Use of healthcare services varied as symptoms increased. A diagnosis of AIDS and a period of more than eighteen months since diagnosis, were both a significant predictors of healthcare and voluntary service use. It was also apparent that the individuals used a variety of healthcare options. Inpatient admission was more likely the more advanced the disease. Living alone was a significant predictor of increased voluntary and healthcare use. Interestingly, those individuals whose main source of care was their GP experienced more referrals on to other specialist services, than those who used the SHC as their main care site. The level of symptoms was not a significant factor in determining referral patterns. An increase or a change of symptoms increased the odds towards hospital admission.

Respondents who were employed had lower utilisation rates than those who were unemployed and /or no longer working. This may be directly related to the fact of maintaining better health.

Living alone was a significant predictor of the use of voluntary services and healthcare. When coupled with a diagnosis of AIDS there was a direct relationship. Living alone was also associated with a increased tendency to seek care from multiple sites and the use of a private physician.

The use of specialist clinics and outpatients was directly related to the primary source of medical care, if it was a GP, then individuals were referred more frequently. There was no relationship between this pattern and symptoms experienced.

The rate of SHC/ GP visits reported in this study, at an average of approximately 24 per annum is only matched by the elderly with chronic disease (Weissert, 1989) and those in the terminal stages of cancer (Greer et al 1986). The study in 1992 in the USA by Mor et al, reported a rate of 30 visits per annum. Differences can be accounted for by the size and the greater diversity of the study population in the American study and in the different pattern of healthcare delivery. The data collected in the pilot coincided with the data produced by Mor et al (1992), both indicate a high level of resource use and do point to the need for obtaining utilisation information from a variety of sources, especially when one considers that the SHC clinic visits account for 7.5 visits per annum. The proportion of individuals receiving care from multiple sources does have implications for the development of cost estimates.

In terms of costs it is apparent that the use of DRG grouping retrospectively may not adequately estimate the costs involved. In the pilot study the movement from one DRG to another was noticeable and this has a significant potential impact upon the overall costs, as does the use of multiple care sites.

From the data gathered thus far there were some preliminary assertions regarding DRGs:

- DRG classification is not static as the disease progresses. Rather, there is movement from one category to another, according to some pattern, but time since diagnosis is not significant in terms of suggesting any form of pattern.
- There may be potential for the development of a composite measure of severity incorporating other areas such as indirect care to assist in the "fine tuning " of DRG categories for AIDS /HIV. This may involve the further exploration of complications and co-morbidity within each DRG category.
- There may be the opportunity from the data being gathered to view DRG categories as the starting point rather than the end point as is the current situation. This may involve the development of a parallel system of classification which incorporates DRGs for inpatient episodes, ambulatory care measures to estimate out -patient and community care needs, and severity measures with disease specific indicators to be used as predictive indicators for the type of care that is required (that is, hospital inpatient care, community care, or hospice or a combination). Patient care requirements could further be determined by the combining of factors such as length of stay and disease specific measures. Other possible features would incorporate determination of the proportion of patients by stage of severity at admission. Therefore, admission rates could be used as a proxy of quality of care.
- It is apparent in any clinical situation that it is the individual who exhibits the obscure and unusual symptoms who consumes the most amount of resources. The concept of the few accounting for the majority is particularly relevant in any area of extremes, for example, intensive care, terminal care. To be able to develop a classification system which accounted for the clinical extremes would be useful in two ways: firstly, it would be very acceptable to clinicians; secondly, it would form an end point detailing the levels and complexities of the highest consumers of health care resources from which other levels could be determined. In other words, knowledge of the extreme and all its

variants (within a DRG category, for example) would enable the development of a scale upon which the various levels could be weighted.

The finding of the GHQ in relation to experiencing symptoms and a high GHQ score, was supported by the findings of Lubeck and Fries (1992) in the USA. In this study it was found that quality of life for individuals who are HIV positive, declines significantly once they begin to have symptoms. Although they utilised a different scale their findings would seem to support the general trend in this study.

The study is clearly limited in terms of numbers and population observed. However many of the bias problems would be countered in the main study as the population and geographical area widens.

It was interesting to note that there was a strong level of consistency between the reported need for care by the patients and the opinions of the staff of the SHC regarding the deficits of care. The role of the counsellor was supported by the reported use of the Community mental health team by those individuals who did not have access to the counsellor.

It was apparent from the views expressed that there is a reported need for:

- education and training of staff in general areas;
- greater co-ordination of services;
- accessible psychological services,
- greater access to specialised HIV/AIDS care on a 24 hour basis.

This was a consistent finding amongst both staff and clients and has significance for planning of future services. To date community care for people with HIV/AIDS has evolved in an uncoordinated manner (Louw 1989, Thomas 1990) and the opinions expressed in this study would support this view.

The use of voluntary agencies have also played a major part in the provision of care. However, it is appropriate to reflect upon the notion that the voluntary services should not be viewed as a substitute for statutory services, such as community nursing, but rather as a complementary supportive service. Given the fact that many of the volunteers are themselves HIV positive, it would be inappropriate to assume that this could be an ongoing substitute for statutory services. One could postulate that as the dependency of the HIV population increases, the availability of volunteers could decrease, given that many of the volunteers are themselves HIV positive (Patton, 1990).

It would appear that there will be the need to describe service use in conjunction with the need for services, and compare this to areas of expressed unmet need. The costs borne by both the individuals and the healthcare system need to be further examined. The ability to access services is a crucial element and reasons for not accessing certain care sites, such as perceived negative attitudes, would seem to play an important part in the choices and decisions made by individuals when seeking care. Levels and sites of care provision also need to be further described.

This pilot emphasised the need for sensitivity when dealing with a vulnerable group for whom privacy and confidentiality are of paramount importance. Issues of respect for confidentiality did impact on the ability to gather data. The individuals concerned did not want their clinical records reviewed. Given the levels of commitment required in a longitudinal study, it was deemed necessary and right, to respect the feelings of individuals and at the same time recognise that the data that they were able to supply were of a rich quality.

The data collection instruments were also reviewed and some re-ordering and re-wording of the questions occurred. The group to whom access had occurred through networking, demonstrated a need for different instructions to be included in the information sheet. During the pilot, one respondent had expressed concern about the fact that questionnaires

were being returned to the author, care of a university department. Concern was expressed that envelopes may be opened erroneously. In order to alleviate this concern the author rented a post office box (at the post office on campus). Given the excellent response rate of the pilot it is assumed that this somewhat minor detail did, in fact, assist in the return of questionnaires, possibly by enhancing the feeling of anonymity. Another change to the questionnaire concerned the addition of blank pages for comments, given the amount that pilot participants were willing to write, about matters relating to how they felt the professionals in the healthcare system treated them, and other thoughts about living and coping with a life threatening disease. This proved, during the pilot to be to be a rich source of data and assisted in confirming "hard fact" with opinions and thoughts.

6:8 Conclusion.

It is important to note that the HIV infected participants from this pilot continued on and formed part of the major study. The method of data collection was successful. It demonstrated that trends in treatment and changes in the disease states could be tracked further and changes, at the group and individual level, would be seen. The treatment options and level of services may change over time but the study design allowed for this to be incorporated. The lessons learned from the pilot about negotiating access and maintaining data confidentiality would prove to be invaluable in the main study. Finally, the relationships built up with the study participants enabled a more sensitive approach to be taken when approaching others.

Chapter 7: Results.

This chapter describes the finding of the main study, commencing with the **interviews of the service providers**. There were a total of twenty-two individuals who agreed to be interviewed, all worked in the Sydney area. In terms of status they ranged from senior hospital doctors to volunteers. Interestingly, some of the respondents not only worked in the area of HIV/AIDS but they also volunteered. The interviews demonstrated that there were conflicts in the delivery of care between various organisations. **Referral** to other services and specialists was based largely on reputations, perceived policies and the requests of patients. It was felt by respondents that referral to services was an "ad hoc " affair and it was not unusual for patients to 'self-refer', either by going to Accident and Emergency departments or by "going private". **Gaps in community service** centred upon provision of psychiatric care. Interestingly, it was felt that there was an over provision of psychological support and concern was expressed about the qualifications of some counsellors. Other areas of service deficiency related to the provision of social and home nursing care, the bulk of which was felt to be falling on the voluntary and family networks. **Coordination of care** was felt to be a haphazard affair, based on personal networks, often it was felt that the only person who coordinated care was the patient.

In terms of unmet need concern was voiced over the accessing of AIDS /HIV care by **minority** groups, particularly individuals of a non English speaking background. Concern was expressed about the Asian community in general, but specifically the Vietnamese community. Other groups of about whom concern was expressed included:

People in the sex industry, especially housewives who although earning money through sex do not consider themselves to be prostitutes. Young men were also seen as being vulnerable, but this may be because little is known about prostitutes as a whole, but male prostitutes in particular are an unknown group;

Homeless people were of concern as they were felt to be vulnerable to exploitation by others;

Men who have sex with men but who do not identify themselves as gay or bisexual.

In terms of practical issues, **housing and finance** were seen as of prime importance and yet appropriate levels and types were difficult for individuals to obtain. **Residential care** was seen as essential yet still lacking despite the advances made by the Anakali house. There was a need expressed for respite care especially for those with AIDS dementia.

Finally, **territorial attitudes** impacted upon the delivery of care, particularly in relation to care management, coordination of care and referral on to specialist and other sources of help. The respondents felt that there was conflict arising between some of the AIDS organisations and medical and other professionals. There was also tension described between members of the medical profession in certain settings.

The second section describes the **results from the self-enumeration questionnaire**. A total of two hundred and ninety-two participants responded, individuals from the pilot group were included. The majority of respondents were gay men, all volunteered. The results demonstrated that individuals who were HIV infected were a highly mobile group, accessing care from a wide variety of sources. Individuals used a combination of general practitioner, SHC and hospital care. The range of symptoms experienced ranged from none through to multiple infections categorising the end stage of AIDS. During the study eighteen people died from AIDS. Individuals used multiple care sites, wide ranging drug therapy with widespread use of AZT and antibiotic therapy for prophylaxis and treatment of opportunistic infections. Alternative therapies were used in conjunction with bio-medical care. In terms of unmet need respondents wanted more home care, and an improvement in attitude from those delivering care, particularly in relation to hospital care. Housing and financial benefits were seen as being difficult to access and currently insufficient to meet needs.

The key trends in terms of healthcare use identified that living alone was a predictor of more frequent hospital attendance and time since diagnosis was a predictor of the need for psychological care. Individuals with pre-existing conditions such as being an IDU or haemophiliac had a greater use of healthcare services, but these admissions were related to their previous health status rather than their HIV state. Persons with AIDS had the greatest concentration of hospital admission and health care use. Over the period of study, on the whole there were fewer admissions to hospital for shorter periods of time and the bulk of care was taking place in the community setting. The main care burden appeared to be borne by personal care networks and community services. It was possible to describe the levels of care needed and used, in relation to the symptoms described, for this group at varying stages of the disease spectrum. However, due to the small numbers involved in the study and the problems of being unable to verify self reported data, the indicators are only indicative of trend not absolutes.

There were significant personal costs described by respondents which related to loss of employment and burdens placed upon personal networks. Inpatient costs were described by the use of cost weights applied to DRGs. This is also only an indicator of trend and it is argued that the use of DRGs is insufficient in ascertaining costs, particularly as there is a greater concentration of healthcare delivered in the community setting. It is argued that a series of cost measures should be applied to the various stages and settings of HIV/AIDS care, in order to accurately reflect the true healthcare costs of the disease work is under way in the field with the development of episode managed units (EMUs) as described by Hindle (1995). The involvement of a wide variety of organisations in the provision of overall care has implications for the levels of service provision and cost estimation. Costs identified but were beyond the scope of this study to evaluate included: costs of premature morbidity, lost income and employment and psychological tolls on HIV /AIDS patients and their carers. The need for psychological support and treatment suggests that, as described by Tross and Hirsch (1988), there is a positive association with being diagnosed as being HIV infected and requiring psychological support.

Chapter 7: Results

For ease of presentation the data and procedure for each part of the study, that is the response to interviews by providers of care and the data captured by questionnaire from the recipients of care, will be described independently, commencing with the provider interviews. The presentation format is the same as the pilot study section

7:1 : The Interviews of Service Providers

7:1 (a) Data Collection: The Interview Schedule.

Following the pilot study the semi-structured interview schedule was altered to include the views of volunteers who provided care. The key areas to be addressed were as follows:

- 1. their individual role and the role of the area where they worked;
- 2. the health and social needs of people with HIV/AIDS and the extent to which these are met by current service provision;
- 3 the co-ordination of services for people with HIV/AIDS.

7:1 (b) The Sample.

The interview sample consisted of individuals currently employed in the following areas:

Sexual Health Clinics, hospitals and hospices, general practice, community health and voluntary AIDS/HIV care.

The range of individuals who volunteered to be interviewed included: general practitioners (GP), hospital/clinic/hospice doctors and nurses, and individuals working in community care both professionally and on a voluntary basis. The breakdown of participants was as outlined in the table following:

Table 7:1 Interview participants and their work designation.

Work designation	Number of participants
General practitioner *	2
Hospital doctor *	2
Hospice doctor	1
Nurse (hospital/hospice)	4
Community Nurse *	3
Counsellor/Social worker	2
SHC doctor	3
SHC nurse *	2
Counsellor	1
Volunteer	2
Total	22

* denotes individuals from these categories who not only worked, but also volunteered in AIDS/HIV care.

Interestingly, four of the respondents both worked and volunteered in the area of AIDS/HIV care. In this instance, these individuals were able to express views on being both a volunteer and health professional. A total of twenty-two individuals participated in the study. All worked in either metropolitan or central Sydney. The sample comprised of individuals who by the very nature of their work and voluntary activity were deemed to be able to provide useful and relevant information on the topics being investigated and are regarded by other health-care workers in the area to have a level of expertise in the field of HIV/AIDS care. The method therefore utilised the concepts of both purposeful sampling (Agar, 1980, Field and Morse 1985, Morse, 1980) and nominated sampling (Diers, 1979, Field and Morse, 1985).

7:2 (c): Method of data capture.

Individuals were initially approached either by the author or another, through a process of networking. Individuals were then contacted by telephone and/ or a letter which detailed the purpose of the interview and reassured respondents that they would not be identified. A total of twenty- eight individuals were approached and asked if they would be willing to participate in the study. Six did not participate, the reasons given were a "lack of time, and pressure of work." One non- participant commented:

"not another study -- you are the eighth person to have approached me in the last two weeks, about being part of a study--thanks, but no thanks".

Whilst this anecdotal it does serve to illustrate the issue that not only have the recipients of care been heavily investigated, so too have the providers. It was also recognised that the health service is an area of employment which is subject to frequent change and flux.

Working in this type of environment does not encourage individuals to undertake work or activities which they feel are going to impinge upon their time.

The interview was carried out at a time and place convenient to the respondent. Individuals were asked if they would be comfortable with the interview being tape recorded.

Respondents were assured that their tapes would be cleared following transcribing, or if they wished, the tapes could be returned to them for their own use. Seven individuals asked that their tapes be returned to them following transcription. After obtaining verbal consent, tape-recorded interviews were undertaken. Interviews lasted between 20 minutes and 2.5 hours, the average length being 1 hour .

7:3 Data Analysis of the Interviews

In accordance with the process employed in the pilot study, all interviews were transcribed in full. Data analysis was largely descriptive, the purpose being to categorise and order the information in such a way as to make sense of it (Brink, 1990) and to identify emerging themes (Polit and Hungler, 1978). The coding of the content of a random selection of the transcripts were checked by one other independent coder, in order to arrive at the areas

categorised for discussion. Thus increasing the reliability and validity of the analysis (Brink 1990, May 1990). No details regarding the respondent, other than a code which indicated employment status and area of work (for example, dsrh indicated a doctor, of senior registrar level, working in a hospital), were retained this was to ensure confidentiality and anonymity.

The main themes will be described, enhanced with the use of direct quotes. Quotes help to "individuate (speakers) rather than blur them into data" (Howarth, 1990:109). According to Weiss (1994:191) quotes stand as evidence that what the researcher has said is "true" and "foster identification" with research participants by "facilitating understanding of their points of view". The discussion following is the product covering the main themes which occurred in the interviews and which were identified by the aforementioned process.

7:4 Interview Findings.

All respondents interviewed had direct care, co-ordination and teaching components in their role. The respondents considered themselves to hold specialist knowledge in the field of HIV/AIDS care, either by virtue of some form of special training and/or the experience of working in the field for some time. Those who were volunteers appeared to have a strong emotional investment. Three of them openly declared that they chose to undertake voluntary work, as they had known some-one who had died of AIDS. Four of the respondents both worked and volunteered in the AIDS/HIV field.

Opinions on the value of specialisation of services for people with HIV/AIDS varied considerably, often reflecting the varied philosophies of their individual disciplines and backgrounds. A key theme which emerged concerned the use of generic services, people with HIV/AIDS were considered to be of low priority in comparison with other groups of clients. It was expressed that this may be due to actual numbers of clients. It was also the opinion of the respondents that there was a degree of "them and us" where individuals

working in generic services appeared to be resentful of the funding being made available to those working in the AIDS/HIV field. This was a repeated and oft voiced opinion.

Service Users.

All respondents commented that they expected the client group proportions to change over time. The majority of clients being seen were still almost exclusively white, middle class, gay men. There were an increasing number of heterosexual IDUs (male and female) who were being seen. Ethnic minority groups, heterosexual men and women were known to be HIV infected but very few were seen. Several respondents spoke about the "hidden populations", by this they inferred that there people who were in denial about their risk of being infected and even if these individuals suspected that they were infected they were not going to accept that they should seek advice/help. This was well illustrated by one respondent:

"We know that there are people who are exposed to risky behaviours. I pass the "wall" (a well known beat) on a daily basis and the trade that is going on there is not all safe sex. There are a considerable number of men who do not regard themselves as gay or bi but still have sex with men. I believe that many of these people would never consider having an HIV test. I am also aware that many of the boys plying their wares on the streets are mostly concerned with earning money not anything else." (General Practitioner).

It was the majority opinion that there were considerable numbers of people, who were not choosing for many reasons such as: denial of their risky sexual practices; fear of community isolation; fear of being HIV positive and the impact that the diagnosis would have on family and friends; scared about the consequences of seeking help and /or advice regarding their HIV status. Although Sydney is the epicentre of the AIDS/HIV epidemic in Australia it does not always mean that people will easily access services. The majority of respondents did note that the mere fact that the gay community was visible compounded the issue about

some groups being part of the "hidden populations". People did not identify with the gay community and as put by one respondent:

"In the minds of the public at large, AIDS/HIV is still a gay disease. I believe that this is partly attributable to the success of the gay community in mobilising themselves and being politically active. But I do feel that this has the potential to backfire, or maybe it already has. Joe Public now has the firm view that AIDS only happens to 'poofers', correlating this with the idea that all gay men are wealthy antique dealers or Qantas stewards. If you are not part of these groups then AIDS won't affect you nor should you attend clinics that care for those "poofers" (SHC doctor).

A final note on the trend of clients attending for HIV /AIDS care. The majority of respondents noted that there had been an increase in the number of young men (under 21 years) being seen with HIV infection, in the past year.

In terms of health status, the clients currently attending the clinic covered a broad range of dependencies and presented with a wide spectrum of infection and disease. One respondent commented that the dependency of current clients was increasing and there were increasing numbers of 'long-term survivors'. The increasing dependency of clients was partly attributable to the increased longevity associated with HIV/AIDS, resulting in people developing more disabling infections and living longer with their sequelae. However there are still considerable numbers of people who have been recently diagnosed and in the early stages of infection. It was the majority opinion that individuals sought care and/or a test to confirm what they already suspected. Six of the respondents were of the opinion that many individuals had had experience of HIV/AIDS and were more than capable of recognising the signs and symptoms, consequently they delayed (and in the opinion of these respondents self medicated) seeking care.

Services provided: overlaps and gaps.

It appears that some services, including information and referral, psychological support, and welfare rights and housing advice are being provided by a plethora of organisations (23 different community groups and organisations were mentioned during the course of these interviews.). Conversely, acute medical and nursing care, residential care, convalescence, rehabilitation, dental and terminal care are provided by a small number of organisations chiefly: ACON, Anakali and the health service.

In relation specifically to home care services, practical help, psychological support, personal care and/or befriending services to people with HIV/AIDS in the community, this role is largely governed by the Anakali network and the other networks which fall under the auspices of ACON. There were a considerable number of individuals with AIDS/HIV who were, in the opinion of respondents, in an income bracket which enabled them to employ private carers. These individuals employ private nurses, therapists, and housekeepers, sometimes through agencies and occasionally by private recommendation. It was the majority opinion, that these people not only had the income to enable them to employ professional help, but because of their social position/status they required that the services they employed were discrete and not overtly connected with AIDS/HIV organisations. It was commented upon that there were an increasing number of home cleaning and nursing agencies which were specifically targeting the gay community by advertising in the gay press. These organisations, according to the respondents, were claiming "sensitivity and discretion" in their caring roles. However, it should be recognised that these data are opinion based and do not give any indication of actual quality or quantity of service by any organisation. Furthermore, the fact that some services are only provided by a small number of organisations does not necessarily represent an overall gap in provision. The data here need to be complemented by information on the need for particular services and the extent to which these needs are met. Individuals were therefore asked to consider:

(a) gaps in service or unmet clients needs

and

(b) areas of overlap in services provision.

Psychiatric Services.

Similar to the findings of the pilot study, the gap most commonly identified were psychiatric services, particularly community based, which were reported to be severely lacking for people with HIV/AIDS experiencing mental health problems. It was claimed that psychiatric staff were currently overburdened and according to one respondent:

"are always made the scapegoat. The fact that psych services have long been under funded and undervalued makes them an easy target. Yet I have to admit there is a need for psych support in the community but that would require more funding" (hospital doctor).

Many of the respondents stated that their clients had or were still in the process of having some form of psychiatric care. Community psychiatric care was seen as necessary and essential to the mental health of clients, however, accessing these services was a time consuming and lengthy process and was frequently commented upon:

"If you need crisis intervention in the community then you can get the psychiatric service, but if you are referring someone for community psychiatric assessment then it's going to be a long wait." (GP).

"You have to wait for the situation to be really bad, then you can get psychiatric help in the community. Sadly, I've known of people who reached such a state that they had to be admitted to psychiatric care, I've often felt that they shouldn't have needed that if only there had been some way to have gotten help sooner" (community nurse).

Service duplication was thought to be most common in the area of psychological support, advice, referral and practical /social support. One respondent did comment that this sometimes led to over-provision of services to individuals and to client confusion. All respondents did feel that despite the potential for overlap, there appears to be a need for a concerted approach and greater availability, in a short waiting time, for help of this type. Concern was expressed at the quality of some services on offer, there was a general feeling that there required to be a "tightening up " of some of the counselling services available. Nine of the respondents commented that they had real concern about the qualifications of some "counsellors". There was a feeling that people with HIV/AIDS are in danger of being exploited by persons who "offer advice based on dubious facts." Of particular concern was the type of advice known to be proffered by some of the more unusual 'New Age' practitioners.

There was an overlap of services in some areas, particularly according to respondents, in the inner city suburbs. According to one respondent:

"At times there are so many groups trying to deliver services its like some kind of weird bazaar. Sadly, it can be become a little vicious with some organisations trying to control and usurp all the others. I feel that the clients often lose out. Personally I do feel that some of the organisations should reappraise who they are trying to serve, some of the larger ones have turned into bureaucratic self-serving monsters. They've forgotten about the clients and their needs and interests" (SHC doctor).

For individuals who worked in the inner city there was a sense of over provision of advice and counselling services but in terms of practical help there was a recognised lack of services. It was stated that by individual staff members networking with voluntary and statutory organisations this type of overlap was consciously avoided at the level of individual clients, however it was felt that some degree (levels not specified) of service duplication was justified to ensure client choice. Problems could arise when one

organisation did try to control the others and there were feelings aroused of competition and animosity. It is recognised that many of these views are coloured by the individual experiences of the respondents and may hold true only for a particular time period.

Minority Groups.

The second most commonly identified area of unmet need was in relation to minority groups affected by HIV/AIDS. In the Sydney area there are large and diverse ethnic communities. Of particular concern was the Asian community, particularly the Vietnamese Community. The Vietnamese community were discussed by the majority of respondents, they were perceived to be more vulnerable than the Chinese community. It is postulated that this may in part be affected by the fact that the Chinese community are long established in Sydney, whilst the Vietnamese are relative newcomers and are visibly located in the less affluent areas of the Western Suburbs. It was felt that cultural and language barriers existed which inhibited and prevented persons of ethnic minority background admitting and seeking help for "at risk" behaviours. Finally in relation to these particular ethnic communities concern was expressed that some people, due to not being legal immigrants, feared approaching any form of organisation, in case of retribution over their immigration status.

Women of a non- English speaking background (NESB) were of particular concern, especially those who were working in the sex industry. Women in the sex industry but not in any form of organised brothel were thought to be very vulnerable. Those women and men who were "street -walkers" and either working on their own or with a "pimp" were seen as in real need of help and support. Opinions were voiced that many worked as prostitutes to earn monies to support their drug habit and if there was the possibility to earn more without using a condom then they were liable to do so. Those who had 'pimps' were often pressured to earn a lot of money although some 'pimps' did ensure that their workers were regularly checked out medically. One respondent noted that there was:

"a not inconsiderable number of housewives who work as prostitutes during the day to earn extra cash. In many ways these women are at great risk . They do not consider themselves to be prostitutes and therefore, I believe they are less likely to practise safe sex and to consider themselves at risk of HIV and other STDs." (GP).

These women and men were thought to be very vulnerable, as were their clients.

Intravenous drug users were seen as a group who were in a double bind of doing something illegal and dangerous and at the same time were less likely to seek help. This group were seen as being difficult to deal with not least because they failed to acknowledge that they had a problem. Several respondents did note that not all IDUs fit into the stereotype of the "street drug addict". Concern was expressed for those individuals who were recreational /occasional drug users, this group were seen as vulnerable.

Men who have sex with men (MWHWSM) and do not identify themselves as gay or bisexual were also seen as a minority group. Five of the respondents felt that they were an extremely difficult group to identify and target. They were undoubtedly, in the opinion of respondents, the most secretive and hidden group.

Finally, four of the respondents expressed concern about homeless people, especially the under twenty year old group. These people were thought because of their lifestyle to be vulnerable. Three respondents were particularly worried about the numbers of young men who were starting to appear as HIV infected. One respondent noted:

"I've noticed a very fatalistic attitude in some of the young men I have seen of late. Many of them are homeless and seem to see HIV as their fate. Many have expressed the idea that they had no hope of living to see their twenty-fifth birthday. One even said that at least if he dies from AIDS he'll be in a comfortable hospital bed at the end." (SHC doctor).

All the respondents were aware of community outreach programmes targeting ethnic groups, sex workers and IDUs but it was still the feeling of the majority of respondents that these programmes were only addressing highly visible groups of these populations--"the tip of the iceberg".

Housing and Financial Benefits

In terms of housing, there appears to be a lack of specially adapted housing and sheltered or supported housing for those who are disabled or highly dependent. In common with the pilot study it was noted that housing services are inundated with demand. However in the city there appeared to be a wider range of waiting times depending on which suburb the individual was seeking accommodation. The range of current waiting times varied from one month to one and a half years, even for the priority list. It was commented that people with HIV/AIDS are being apparently ranked with other vulnerable groups, with the result that only those who were relatively ill were given high priority.

Concern was expressed about the problems of individuals living in private rented accommodation. Despite the current anti-discrimination statutes, there were cases of people being evicted when knowledge of their HIV status became known. Respondents spoke of the strange dichotomy of there being protective legislation and yet individuals were still vulnerable. As noted by one respondent:

"but for people in an emotional and distraught state the last thing they were likely to do was to invoke the powers of legislation, especially when their need was for a roof over their head" (community nurse).

There was concern expressed regarding the problems of maintaining individuals in their own homes when there was a lack of assistance and/or problems with families. The majority of respondents were of the opinion that there were many people with HIV who

were actively seeking alternative accommodation. Reasons cited included problems with current accommodation specifically, increasing difficulty with stairs, ineffective heating/air conditioning and insufficient toilet facilities.

On the other hand, the lack of a home or the availability of only make-shift, temporary accommodation may have direct repercussions on the health of persons with HIV infection and as noted by three respondents will also severely impinge on the ability of the individual to get home care and other community services. Individuals who were in temporary accommodation were of concern especially those who lived in hostels.

Similar limitations affected the provision of financial support, another area of unmet need according to respondents. The system for claiming statutory benefits and allowances was considered to be slow and complex. People who are HIV positive but not unwell faced similar problems to people who were quite ill, but did not meet the criteria for some benefits and allowances. Finally it was the general consensus that the income offered to people who were ill and unable to work was woefully inadequate to meet their needs. It was noted by several respondents that many gay men had never had to claim benefits before and they were entering a completely alien environment. Two respondents were aware of a project in the design stages which was looking at the problems and extent of poverty of gay men who are HIV infected.

Residential Care

A further major area of under provision was apparently that of residential care in a non-hospital setting. This applied both to those individuals (who may or may not have carers) who might require care on a long term basis, as the levels of dependency rises, in order to maintain them in a non-hospital setting and on a more short-term basis for people requiring rehabilitation, convalescence, respite or terminal care. The Anakali house project has done much to assist this problem, however, two of the volunteers noted that there

always seemed to be a demand for places. Short term respite care accommodation remains a priority, particularly for people with AIDS dementia and their carers.

Gaps in Community Services

Although there was a general consensus among respondents that it was desirable for people with HIV/AIDS to be cared for in their own homes, many felt that there were major gaps in the provision of community services, particularly when intensive support or continual 24-hour supervision was needed. The community nurses and general practitioners in this sample described that for them often caring for people with AIDS/HIV was just one more burden. Reference was made to the fact that if it became known that you were gay or sympathetic to gay people, your workload began to grow. There was an acknowledgment on the part of these participants that some of their colleagues were uncomfortable dealing with gay and/or HIV infected individuals.

People with HIV/AIDS often required practical assistance, such as help with shopping, cooking, cleaning and so on. In this respect, statutory support services were reported to be extremely inadequate and voluntary agencies were depended upon greatly to provide this kind of assistance.

The respondents were united in the opinion that as numbers of people who are HIV positive and increasingly dependent increase, there will inevitably be a greater reliance on informal care. Those who volunteered were of the opinion that there were many people who simply would not be able to remain at home without the volunteer networks and support. As two volunteers commented:

"I have been a volunteer for the past five years. In that time I have seen the numbers of people who require help almost triple. Also, as a volunteer I am being asked (I

am OK about doing it) to do more and more sort of complicated nursing care. It seems as though there are not enough community nurses around to cope" (volunteer).

"There just seem to be more and more young people out there with this rotten disease. Their families don't want them and sometimes even their lovers and friends turn their backs on them. Yet they want and need to stay in their own place for as long as possible. They need volunteers, anyone, someone to help them remain at home and have some personal dignity." (volunteer/hospital nurse).

All the respondents were of the opinion that the need for respite care and support services for informal carers would continue to grow as the dependency of those infected increased.

Referral to other healthcare services.

Referral to other health services seemed to be a mixture of several issues. One is the (perceived) need to refer to another specialist within the same health authority. There was the implication that this was policy and was perceived as a "cost control exercise". There was the dichotomy of wishing to refer to people who had the "good reputations" and having to wait as they had an abundance of referrals or going to someone else in order to ensure that the patient was seen quickly. Knowing who to refer patients on to seemed to be a rather "ad hoc" affair, based upon such issues as reputation and being personally known. Otherwise referral was based upon a client requesting referral to a particular site or person.

It was also noted that clients themselves were in many instances choosing their care providers, to the extent of travelling to another state in order to access particular individuals. As one general practitioner noted:

"I frequently find that patients have tried out several sources within the city and indeed interstate. Indeed, a couple of my patients have been overseas, Europe and the US

primarily. Although I do know of one individual who went to Nepal as he had heard that there was a particular herbalist there. People will go to great lengths and expense to seek 'miracle cures'".

Fear of breaching client confidentiality was an issue that was paramount to all respondents. It was also noted that many of the respondents who were doctors did not always feel confident that they knew sufficient about the patient, their drug taking and symptoms to adequately refer them on to a specialist. The impression was given that there was a degree of anxiety as to whether or not patients were always imparting all pertinent information. As expressed by one doctor:

"How can you accurately refer a person onto some eminent individual when they only tell you half the story. It's very difficult to confidently refer them onto a specialist especially when you discover the symptoms they were describing were due to a combination of drugs most of which you didn't know they were taking" (SHC doctor).

It was recognised by respondents that this problem of partial information was due to a fear of 'missing out ' on the latest drugs, fear of breach of confidentiality and the 'shopping around' approach taken by many of the patients when accessing care. From the comments made it seems as though referral and subsequent accessing of care is not as straight forward as it might be, there appear to be the barriers of knowing who to refer to coupled with the fear held by clients that their privacy may be breached albeit unwittingly. A comment was also made that it is difficult to refer a patient onto a specialist when they do not give the same name to both parties.

"The number of Bob Hawkes and Fred Niles who attend the clinic would make it difficult to refer them all on. I feel that patients access hospital care largely by way of crises-- they are simply so sick that they have to be admitted to hospital-- self referral!!" (SHC doctor).

This view was reiterated by individuals working in both the hospital and community setting.

"Really most people refer themselves either by just turning up, going private or by arriving into hospital via cas{casualty}" (Hospital doctor).

It would appear from comments made that the main source of referral to hospitals and by default specialists was via Accident and Emergency departments (casualty). Professionals seemed to feel that they had very little control over patient referral and when they did they were unsure about who to refer patients to within the hospital system, often using the information supplied by patients or other professionals.

What are the needs of people with HIV/AIDS and are the needs of those with HIV unique?

Respondents did not equate the needs of people with HIV/AIDS as being the same as those with cancer.

"With cancer, treatment is improving all the time, but there is no cure for AIDS. I don't think I'll see one in my professional lifetime" (Hospital doctor).

"Cancer does not have the same degree of stigma as AIDS" (community nurse).

"AIDS affects the young almost exclusively, cancer is more a disease of the middle and old age groups" (GP).

The respondents were vocal in their view that HIV was more than a chronic disease. They felt that HIV was inexorably linked with sex and as such was greatly stigmatised. Cancer was not seen as having the same stigma, after all as commented by one respondent:

"Even in death people with HIV/AIDS are placed apart, that doesn't happen with cancer patients nor have we had to instigate legal moves to actively protect cancer patients" (hospice doctor).

It was the general opinion that drawing parallels with other chronic diseases was unhelpful and did not reflect the enormity of the impact of the disease on individuals and the healthcare system.

Factors influencing the needs of people with HIV/AIDS.

A number of factors were thought to influence the needs of people with HIV/AIDS and to differentiate between HIV/AIDS and other chronic illnesses. Stigma was the commonly mentioned factor by all respondents. There is a great deal of evidence indicating that the stigma associated with HIV/AIDS results in prejudice, ostracism, harassment and oppression; all of which were reported as common problems by respondents in this study.

All of the respondents considered the fact that most people with HIV/AIDS are facing a life-threatening and potentially disabling disease at an early age was another unique factor. This not only made acceptance of help problematic, but also affected the acceptance of help, since those affected are usually not used to being in a dependent role.

The multiplicity of treatments available and the power of the consumer group, primarily the gay community, made this a different environment in which to deliver care. Most respondents were of the opinion that AIDS is a disease in which consumer choice is playing a great role. Never before has a group of consumers had the power to not only contribute to care design, but because of the available wealth of the community affected, to access care at their choosing. All the respondents mentioned the fact that in Australia, the gay community had played a political and influential role in the provision of care available. Due to the levels of disposable income available to some members of this group many individuals are able to

travel and access care on a 'user pays' basis. However, comment was made that in some ways this has contributed to the myth of the 'wealthy gay man with AIDS' who is able to freely access services. This does not take into account the fact that AIDS affects all spectrums of society and it was the opinion of the group that they are seeing more and more individuals who are not part of the stereotypical gay scene. Many patients are from low socioeconomic groups and have poor levels of education, many are homeless and belong to ethnic minority groups who are not able to demand care and treatments.

All the respondents thought the modes of transmission of HIV through sex and injecting drug use added to the stigma associated with the illness. Furthermore, HIV brings to the fore a whole range of issues which are linked with social taboos in Western society, including sex, particularly homosexual sex, drug abuse, racial discrimination and death.

The number of drug trials and information about the same was seen as a problem. Individuals are being constantly bombarded with information and in the words of one respondent:

"there is a lot of misinformation and rumour about treatments available. The media don't help, every time there is an article about AIDS clinic numbers rocket the following day" (SHC doctor).

The number of "alternative" treatments and therapists does not help the situation according to respondents. Anger was expressed about the potential and actual exploitation of vulnerable people, by individuals who were seen by respondents, to be preying upon the susceptibilities of scared individuals. Concern was also expressed about the efficacy of some of the treatments which patients were taking in combination with other therapies.

Common needs of people with HIV/AIDS

There was agreement amongst respondents on the common needs of people with HIV and AIDS. Those identified include:

- access to continual counselling and psychological support at various stages throughout the illness, including psychiatric services where necessary.

There was a codicil added that all therapists and counsellors should be licensed and have undergone some form of accreditation.

- access to specialist clinical services, without the need to resort to crisis measures;
- non-discriminatory, supportive attitudes and care from all professional and non-professional service providers;
- strict policies and assurances of confidentiality;
- advice and advocacy in relation to welfare rights;
- easy access to a range of social support services;
- increased amounts of services in line with the services provided by the Anakali house;
- provision of appropriate housing and modification of existing housing;
- easy access to practical assistance with domestic and other practical tasks, for example, cooking, shopping, and so on.
- specific dietary advice and access to appropriate meals services/help with cooking;
- intensive community support when ill, including 24 hour cover for highly dependent clients;
- services specifically for informal carers to offer support;
- an increased number of appropriately trained staff in both the voluntary and professional sectors in order to deliver quality care;
- the development of specialised home based terminal care services and the 'hospital at home' in order to maintain patients at home for the duration of

their illness.

There was agreement that all services should offer a rapid response and be flexible.

Service Coordination.

People with HIV/AIDS use a broad range of services, the coordination of these services was in the opinion of respondents chiefly managed by patients themselves. There were stated problems with coordination of services arising from there being no one person nor site in control of the management of care. It was felt that there was duplication of services to some individuals whilst other missed out completely. It was expressed that gay clients relied greatly on volunteer and ancillary groups to manage their care programme. It was felt that gay patients frequently were offered better services because of their visibility, but individuals who were not gay or did not identify with the gay community fared less well in the distribution of services. It was the majority opinion that living in certain parts of Sydney also affected the coordination of services. Those individuals who lived in the suburbs of Paddington, Annandale, Newtown and similar were more likely to have a wider range of services and a greater possibility of managed, coordinated care. A key problem in the coordination of care was the fact that patients were constantly 'flitting' from one care site to another in order to maximise their choices. Concern was also expressed as to the power plays that would evolve when care is coordinated, the question arose as to who would be the person most able to service and assist the needs of the patients. As some respondents said:

"Coordination is an excellent idea, but who is going to do it ?" (community nurse).

"How can you coordinate services for people you only know by a pseudonym?" (SHC nurse).

However, respondents in this study generally felt that co-ordination was non-existent, due in no small part to the problem of the mobility of the clients served and the plethora of groups in some areas available to deliver services. Every respondent made some criticism of service co-ordination. Typical comments included:

"Co-ordination is a hap-hazard affair..it's all about calling in personal favours and using long established contacts " (GP).

"So many people, so many meetings, all accomplishing very little" (SHC nurse).

"At times it seems as though its all about who can shout loudest and longest. I could spend my entire working life attending meetings, achieving very little" (counsellor).

It was recognised that there was a need to hold meetings to attempt to coordinate care, to forge links between service providers and exchange information and views. The service co-ordination that did occur appeared to take place informally and at individual client level. However, the holding of case conferences on a regular basis involving all those involved in providing care for a single client was rare. The setting up of such meetings was fraught with logistical difficulties and confusion.

Problems of co-ordination appeared to be particularly acute between the medical and community nursing services and the various agencies providing community care. Some of these problems appeared to stem from the fact that many patients "shopped "around for their medical care and treatment but also were in receipt of community care on a voluntary or private basis, occasionally this caused mis-understandings between the various agencies. Liaison with a large number of community workers and voluntary groups across a wide area was felt to hamper any co-ordination.

Territorial Attitudes.

A further barrier to service co-ordination was the reported "territorial" attitudes of certain organisations and individuals who were apparently reluctant to refer clients on to others for help. There was a tendency to try to cater for all needs through one service.

There was some evidence of antagonism between professional medical/nursing staff and certain other agencies. From the comments received this may have been due, in part, to poor understanding of the roles, skills and abilities of other personnel from both parties. Attitudes were felt to hinder coordination of care and could have the potential to limit client's access to care. There was reported 'in fighting' within the higher echelons of the medical profession as to who was best suited to treat individuals with AIDS. This caused a degree of reluctance to refer patients to certain individuals as one respondent noted:

"If I refer to Dr X at Hospital Y then he takes over the patient entirely, even when he discharges the patient, he doesn't have the courtesy to let me know that the patient has been discharged. I wish he would just be courteous in his dealings with me. I'd send people to someone else but he's good at his speciality" (GP).

There was a feeling that AIDS has really 'made the careers of some individuals' with the implication that this has not always been in the best interests of patients. There was a considerable degree of antipathy towards some of the AIDS organisations. These organisations were felt to be infringing upon professional domains and encroaching upon territories. The worth of these organisations in terms of fund raising and political lobbying was applauded, but there was a strong feeling that these groups were moving too far into medicine and other domains.

Those respondents who were also volunteers spoke of the dichotomy and personal conflict that they found in both working professionally in the field and being a volunteer. They

noted from their volunteer perspective that their skills were devalued by professionals and their opinions rarely sought yet they frequently had had more contact with an individual. Some of their fellow volunteers thought that they must have ulterior motives in wishing to volunteer and work professionally with AIDS patients. These people were of the opinion that volunteers were grossly undervalued and were currently bearing the brunt of the care burden, often in lieu of families.

Summary

The increasing spread of HIV and the level of demand this will place on services occurs in the context of service quality, appropriateness and effective resource use being scrutinised by health service planners. The interviews indicate the broad range of needs experienced by people with HIV/AIDS and highlight some of the shortcomings of current services. The illustrated problems associated with the co-ordination of service must have an impact upon the eventual quality of service received by the clients. Albeit that these were the opinions of a small number of people working in a diverse geographical area, the opinions are valid given that they reflect the environment in which the individuals are delivering care.

However it does seem apparent that individuals are working in an area where the necessary co-ordination of services is hampered by a lack of time and the possible reluctance of other agencies to become involved, this was not stated explicitly but was inferred in the comments. This factor alone will have an impact upon the quantity and quality of services offered.

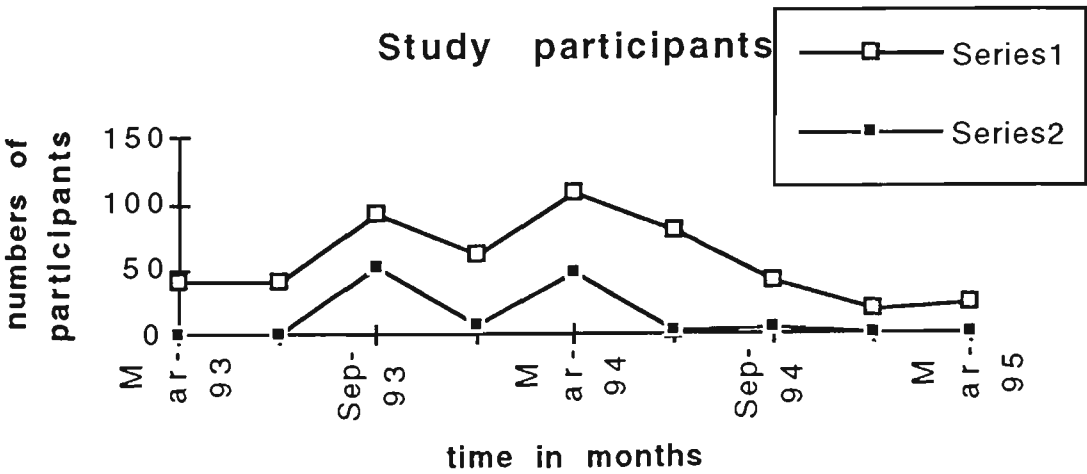
The areas of unmet need identified relate not only to the specific health care needs but also to the social care needs. Barriers to care access were identified as being both professional and social, illustrated by difficulties in referral to other care sites and social barriers such as ethnicity.

7 2: The results of the self-enumeration questionnaire.

All data from the study were entered into a database using the software package Excel 4. Individuals were not identified, except by a number. The link between the number and the individual was known only to the author and was not kept in any written format. As the study expanded so did the database and individuals from the pilot continued to be followed at three to six monthly intervals, in conjunction with new respondents, in order to enhance the quality of longitudinal data available.

During the period March 1993 until March 1995 there were a total of five hundred questionnaires returned. From September 1993 until March 1995 there were a total of one hundred and fifteen 'new' participants, the numbers lost over the same period equalled ninety-seven. There had been no losses to the original forty participants from the period March 1993 until September 1993. A total of two hundred and ninety two individuals participated in the study. The graph following details the total number of participants each month with the 'new/returned " participants.

Figure 7:1 The pattern of response by participants during the period March '93-March '95.



Series 1 is total number of replies per month; Series 2 is the number of new/returned respondents.

The periods of December until March in both 1993 and 1994 were the times of the lowest number of returns. It is surmised that as this is the summer holiday period many respondents had temporarily moved out of the city and hence the lower number of replies. The reasons for attrition from the study are detailed in the table following. It can be noted that for the majority of respondents reasons for attrition were unknown. There were no known duplicate responses, although as many respondents only identified themselves with a symbol (in one case a red star) or initials, there was the potential for duplication. However, on entering the data the questionnaires were checked in terms of content. Interestingly, there were no obviously erroneous nor incomplete returns. It is surmised that given the length of the questionnaire, if respondents did not wish to participate they simply did not complete a form. There were many "one -off" respondents. In effect, this was not a problem as the intent was to look at the use of healthcare at varying stages along the HIV/ AIDS continuum. Their continued response would have been gratifying, but it was recognised that respondent mobility and attrition was a central issue in carrying out a study of this type. Individuals moved in and out of the study on a frequent basis, reasons for the movement are largely unknown.

Table 7:2 Reasons for Attrition.

<u>Reason for Attrition</u>	<u>Number</u>
Imprisonment	3
Moved interstate	16
Travel overseas	17
Moved out of Sydney/Illawarra area	2
Death (AIDS)	8
Death -Road traffic Accident	1
Unknown	40
Total	97

Demographic Characteristics

Of the two hundred and ninety-two HIV infected individuals all but four were men. Sexual orientation could be assigned for two hundred and eighty-six (97.9%): two hundred and thirty-six (82.5%) were homosexual, twenty-eight (9.7%) bisexual and twenty-two (7.6%) heterosexual. Four respondents identified themselves as injecting drug users and two as haemophiliacs. A total of sixty -four (21.9%) respondents identified themselves as having an AIDS diagnosis, at the first point of contact. In addition twenty-seven of the study population progressed to AIDS during the study period: twenty-seven (88.8%) homosexuals, two (7.4%) bisexuals and one (3.7%) heterosexual. Thus out of the total population surveyed, ninety-one persons (31.1%) had an AIDS diagnosis. Of all subjects, nineteen were known to have died including eighteen of those diagnosed with AIDS (the other died in a road traffic accident). The age range of those who were HIV positive was 17-59 years, the mean was 34.2 years. The mean age of death from AIDS was 38.7 years. There was no significant difference in mean ages observed between individuals of different sexual orientation.

In terms of race, two hundred and sixty -four (90.4%) were Caucasian, six (2.0%) Asian, three (1.02%) Aboriginal, and nineteen (6.5%) were Maori /Polynesian. The majority of respondents (85.9%) described themselves as single, 3.7% as married, 7.1% as divorced, 2.3% as separated and the final 1.71% were in a “de facto” relationship. The question related being in a relationship to a woman. The table, following, demonstrates the marital and co-habitation status of the respondents.

Table 7:3 Marital and Co-habitation status.

<u>Marital status</u>	<u>Number</u>	<u>Percentage (%)</u>
Single	251	85.9
Divorced	21	7.19
Separated	7	2.39
Married	11	3.76
"De-Facto"	5	1.71
<u>Co-habitation Status</u>		
Alone	151	51.7
Parents/ Family	22	7.53
Husband/ Wife	16	5.47
With Lover	58	19.86
With Friends	27	9.24
In a Shared Property	18	6.16

It is notable that the majority of respondents were single and lived alone. This group covered all ages and stages of the disease. It is postulated that that this group could place greater demands on the health and social services as their disease progresses. In terms of residence one hundred and eighty-seven (64.04%) respondents stated that their main place of residence was Sydney and its suburbs, thirty seven (12.67%) lived in the Illawarra, forty -two (14.38%) lived in the rural areas and interestingly, nineteen (6.5%) came from other states. Finally, there were seven individuals (2.39%) who although Australian residents were not currently living in Australia, yet appeared to be returning to seek healthcare.

Occupational status was as follows: one hundred and seventy-nine (61.3%) were professionals, forty-seven (16.09%) were non-professionals, fourteen (4.79%) were students and fifty -two (17.8%) were unemployed. Fifty of the group who were unemployed had an AIDS diagnosis. Interestingly having an AIDS diagnosis did not always equate with being unemployed, out of the ninety-one respondents with an AIDS

diagnosis in the study, fifty were still employed, twelve others were known to be still working but on a reduced number of hours and finally, four were currently pursuing other career options, primarily, in the arts -- sculpting, writing and photography. These four respondents were keen to make it clear that they were not unemployed and were self-financing from savings.

Living alone was associated with being a professional worker and was also associated with having a private physician and increased attendance at a clinic or doctor's surgery.

Individuals with a private doctor visited them more often than those individuals whose usual source of medical assistance was a Sexual Health Clinic.

Knowledge of HIV status by others, was not significant amongst any of the groups. Table 7.4 following, details the spread of other individuals who know the HIV status of the respondents. It is interesting to note that one hundred and eight (36.9%) of all respondents had restricted the knowledge of their HIV status to their close/intimate contacts. This result may indicate that individuals fear the reactions of others once knowledge of their HIV status has been revealed. However, this is only conjecture of the part of the author. From these results it appears that forty-seven individuals have to cope with their diagnosis and sequelae without support from personal networks. It is recognised that these people may have chosen not to involve others. The reasons for them not telling others about their HIV status are unknown.

Table 7:4 Knowledge of HIV Status (by others).

<u>Those Who Know</u>	<u>Number</u>	<u>Percentage (%)</u>
No-one	47	16.09
Lover Only	32	10.95
Parents Only	20	6.84
Husband / Wife	9	3.08
Family & Close Friends	101	34.5
All Personal Contacts	83	28.4

There was a direct correlation with time since diagnosis (greater than three years) and family and close friends being aware of the diagnosis ($r=0.81$). For the respondents whose diagnosis was unknown to any personal contacts, the majority (62%) lived alone and only one person had an AIDS diagnosis. In this group the respondents were either asymptomatic (32%) or were experiencing few symptoms (less than three infections of note), there was a direct correlation ($r=0.77$) being diagnosed less than twenty-four months, and having told no-one about their HIV status. There were no other results of note.

Broadly speaking, the respondents were middle-class, white, gay men and as such they are representative of the HIV/AIDS population in the Sydney region. The respondents encapsulated a wide range individuals from those who were recently diagnosed and asymptomatic through to those who were experiencing multiple infections and AIDS. For ease of presentation the respondents were categorised into the following disease stages:

Asymptomatic (n=87); Symptomatic HIV(n=114) and AIDS (n=91).

7 2 CLINICAL CHARACTERISTICS OF THE SAMPLE.

7:7:2(a) THE RESULTS FROM THE MENTAL HEALTH QUESTIONNAIRE.

Using the 28-item GHQ (Goldberg Mental Health Questionnaire) and scoring GHQ method (0-0-1-1), the mean mental health score for asymptomatic individuals was (n=87) 5.2.(SD= 3.3; range 0-26) whilst for those with AIDS, the mean mental health score was (n=91) 13.6 (SD= 4.2; range 3-28). Using the recommended threshold score 4/5 (Goldberg, 1978), 70 of 292 (24%) had evidence of poorer mental health, 103 (35.3%) scoring 12 or above, which would indicate a need for professional intervention. Table 7.5, following, describes the results.

Table 7:5 Frequency of Total Mental Health Scores on the 28-Item General Health Questionnaire

GHQ score	Asymptomatic HIV (n=87)		Symptomatic HIV (n=114)		AIDS (n=91)	
	No	%	No	%	No	%
High (12-28)	22	25.3.	47	41.2	34	37.4
Mid (5-11)	10	11.5	21	18.4	39	42.9
Low (0-4)	55	63.2	46	40.4	18	19.8

A series of 2 x 3 Chi-squares analyses to investigate whether any of the group (asymptomatic, symptomatic HIV and with AIDS) reported a greater frequency of poorer health, at any particular stage during their disease, were undertaken. For individuals who were asymptomatic yet had been diagnosed as HIV infected for less than three months there was a statistically significant result ($p<0.05$; $df=3$). An AIDS diagnosis and having been diagnosed as HIV positive for more than five years, was significant in attaining a high GHQ score ($p<0.05$; $df=2$). There were no other significant results using Chi squared tests. It was noted that there was a direct correlation between experiencing symptoms and a high GHQ score ($r=0.94$). It was found that all persons who had been diagnosed for three months or less and for more than 36 months and who were experiencing symptoms reported high GHQ levels. Individuals with AIDS and who were experiencing multiple symptoms

from the various opportunistic infections were found to report high GHQ scores. Table 7.6 describes the frequency of scores for the four key areas of the GHQ. It can be seen from this table, that the respondents with symptomatic HIV infection and AIDS, reported levels of change of mental health that would cause concern. This may be due to the fact that these individuals feared for their mortality, independence and general well-being. It was notable that upon experiencing physical symptoms, individuals reported a change in their perception of their general feeling of well-being. Those individuals who were newly diagnosed yet were asymptomatic and those who had been diagnosed for less than six months but were experiencing symptoms, recorded high GHQ scores.

Table 7:6 Frequency of scores on the 28 -Item General Health Questionnaire.

	<u>Asymptomatic HIV</u>		<u>Symptomatic HIV</u>		<u>AIDS</u>	
	No	%	No	%	No	%
Somatic Symptoms						
HIGH (3-7)	19	12.8	49	43.0	46	50.5
(2)	8	9.2	22	19.3	36	39.6
Low (0-1)	60	69.0	43	37.7	9	9.9
Anxiety & Insomnia						
HIGH (3-7)	16	18.4	42	36.8	41	45.0
(2)	11	12.6	15	13.2	30	33.0
Low (0-1)	60	69.0	57	50.0	20	22.0
Social Dysfunction						
HIGH (3-7)	21	24.1	67	58.8	32	35.2
(2)	24	27.6	13	11.4	48	52.7
Low (0-1)	42	48.3	34	29.8	11	12.1
Severe Depression						
HIGH (3-7)	19	21.8	39	34.2	31	34.1
(2)	1	1.1	15	13.2	50	54.9
Low (0-1)	67	77.0	60	52.6	10	11.0

The odds ratio indicated that persons in the following time frames since diagnosis, 6 months and less and 36 months and more, were 6.84 times more likely to score highly on the GHQ. Those with an AIDS defining disease were 8.1 times more likely to score highly on the GHQ.

DRUG USE AND REPORTED SYMPTOMS.

This section deals with prescribed drugs and non -prescribed drugs which people reported using over the study period. The drugs which are currently being given to HIV infected individuals are all reverse transcriptase inhibitors, such as AZT, ddC, ddI, D4T and 3TC, which inhibit the replication of the virus within cells. However, it appears that the benefit from these drugs is only transient as the virus is able to change and become rapidly resistant to each new drug regimen. In this study 19 symptomatic HIV respondents were on ddI, all went to a GP for care, the majority (78) were on AZT, thirteen respondents did not report being on AZT or any other anti-retroviral. Interestingly, all thirteen respondents had been diagnosed as HIV positive for more than 5 years. It is unknown whether they chose not to take AZT or whether clinically they were unable to do so. Finally, two respondents were taking 3TC, they were enrolled in a clinical trial at John Hunter Hospital, Newcastle. They were normally resident in Sydney but travelled to Newcastle specifically to be part of the trial. Both respondents also had homes in the Newcastle/Hunter valley area.

Other medication taken was in direct relation to symptoms experienced. During the course of the study, eighty-seven (29.7%) of the HIV positive people were reportedly asymptomatic, the rest all experienced symptoms on a constant (reportedly daily) basis. The main signs and symptoms experienced by the remaining respondents were as detailed in the table following:

Table 7:7 Prevalence of signs and symptoms among the 205 respondents who experienced symptoms.

Symptoms	Number	%
Burkett's lymphoma	4	2.0
Parathesias	6	2.9
CMV	6	2.9
Septicaemia	9	4.4
Faecal incontinence	12	5.9
Vomiting	16	7.8
Psoriasis	18	8.8
Abdominal pain	19	9.3
Dyspnoea	22	10.7
Cahexia	23	11.2
Hallucinations	38	18.5
Skin disorders (generalised)	43	21.0
Nausea	49	23.9
Anaemia	52	25.4
Urinary incontinence	57	27.8
Kaposi's Sarcoma	58	28.3
Low platelet count	75	36.6
Diahorrea	76	37.1
Mouth Ulcers	81	39.5
PCP	87	42.4
Retinitis (CMV)	92	44.9
Herpes	98	47.8

Table 7:7 continued

Fever	101	49.3
Fatigue	111	54.1
Joint pain	123	60.0
Headache	136	66.3
Cough	143	69.8
Weight loss	152	74.1
Thrush	167	81.5

All respondents with AIDS are included in the above figures. It should be noted that individuals experienced multiple symptoms, particularly those who had a confirmed AIDS diagnosis. There was a direct correlation between the experiencing of multiple symptoms and having AIDS ($r=0.92$). As can be seen by the list the respondents were party to a full range of opportunistic infections. There was a high prevalence for weight loss, thrush, headache and for pain in its various manifestations and localisations.

Table 7.8 details the drugs taken in relation to each of the opportunistic diseases. As can be noted from this table although there are a wide range of drugs employed, this list may not be exhaustive, but it was those drugs as outlined by the individual.

Table 7:8 Reported Drug use in relation to treatment of Opportunistic Infections

<u>Infection</u>	<u>Reported Drug Use</u>
Candidias (Thrush)	Topical: Nystatin, Amphotericin B lozenges Systemic: Fluconazole, Ketoconazole
Cytomegalovirus (CMV) & CMV retinitis	Gancyclovir (DHPG)[intravenous and oral], Foscarnet
Cryptosporidium Diarrhoea	Codeine; Lomotil;
Herpes (Simplex& Varicella Zoster)	Acyclovir
Kaposi's Sarcoma (KS)	Chemotherapy,
Mycobacteria Avium (Fever)	Paracetamol plus those listed below for MS
Mycobacteria Septicaemia (MS)	Rifabutin, Clofamazine, Isonazid, Ethambutol, Zithromax, Biaxin,
Pneumocystis Carinii Pneumonia (PCP)	Dapsone, Co-trimoxazole, fandisar, Bactrim; Cortisteriods especially cortisol, Pentamidine, TMP/SMX,primquine/clindamycin
Wasting Syndrome	Testosterone, steriods

It is also recognised that some of the symptoms experienced could be a direct result of the level of drug therapy being used to treat particular symptoms. It is known that some of the medications are given as prophylaxis. For example, dapone and bactrim are given as prophylactics for PCP when the individual's CD4 count drops below 200. Drugs were taken in combination of not less than four drugs at any one time for 63% of respondents on drugs. Although prescribed not all drugs were taken. Twenty-seven respondents said that

they had been prescribed AZT but they had stopped taking it. It is recognised that the same could be true for other medications, but respondents did not comment to this effect. There was a direct correlation ($r=0.81$) with the number of drugs taken ($n=4$) and stage of the disease (AIDS). Patients with AIDS took three times more drugs than those who were experiencing HIV symptoms. Not all drugs are prescribed, 27 respondent who were experiencing wasting syndrome were taking marijuana. It was reported in the journal *Australian Doctor* in the issue of 24th March 1995 (p 64), that Dr Abrams of San Francisco, has anecdotal evidence that marijuana is effective in restoring people's appetites. There a legal problems such as getting sufficient quantities of the drug to undertake a clinical trial. Only drugs taken in relation to HIV/AIDS were recorded in the study. For example, the drugs taken by haemophiliacs specifically for their haemophilia were not detailed. The majority of respondents (95.5%) took vitamin supplements. The amount of proprietary medications which were being consumed in respect of pain (respondents = 149) were substantial. Drugs mentioned included: paracetamol, Tylenol, codeine, aspirin, disprin, distalgesic and panadeine. Prescribed pain relievers included: naprosyn, codeine phosphate, fortran, indomethacin, ibuprofen and morphine tablets.

There was no apparent pattern with symptoms experienced and time since diagnosis. There were two exceptions. There was a direct correlation with having Kaposi's sarcoma ($r=0.78$) and having been diagnosed more than 24 months, this is the same as for individuals in the pilot study. PCP was directly correlated ($r=0.86$) with having been diagnosed for not less than five years and having an AIDS diagnosis. This can be explained in part by the fact that this study uses time since diagnosis which could be different to the time of sero-conversion. All individuals with Kaposi's sarcoma and Burkett's lymphoma had chemotherapy over the study period.

It is notable that three respondents commented that they were taking IL2, which is a reverse transcriptase drug, but one which is still undergoing clinical trials in the US. It is not available in Australia. Both respondents had recently returned from the US and Germany,

the drug is supposedly available in both countries but on a limited basis. This is of concern as the drug taking is not able to be monitored as stringently as one would hope.

There was no significant difference between the drug regimens employed by SHCs and GPs. Length of time on drug therapy ranged from 2 weeks through to 6.5 years. Length of time was directly correlated with the time since diagnosis, particularly in relation to therapy with AZT.

HEALTHCARE USE.

One hundred and thirty seven of the respondents stated that their key source of medical help was their General Practitioner (G.P), seventy used Sexual Health Clinics (SHC), the rest used a combination. It is notable that the seventy persons tended to use the SHC for care which they perceived as being HIV/AIDS related. The level and assumptions on which the decisions were made as to which source of care to approach are not known. It is important to note that the respondents who used a SHC as their main source of care, also reported using at least one other source of medical care. The respondents who used their GP as their usual care source, also reported using other sources of medical care (accident and emergency departments and 24 hour medical clinics). The absolute rate of medical care use averaged 10 GP/SHC visits per annum.

Reporting symptoms correlated with having a high frequency (more than 7 visits in 14 days) of visitation to a GP. Interestingly, this was only the case for those persons who used a general practitioner /private physician as their main source of medical help. Persons with the same level of symptom intensity, but who used the clinic were less frequent attenders. This may be due to accessibility, but reasons for this are currently unknown.

Being unemployed was associated with a more frequent use of hospital, clinic and GP facilities. This may be explained by the fact that the majority of those persons who are

employed reported fewer symptoms and therefore perceive themselves to be in better health. It is recognised that simply being able to continue working does seem to indicate less health problems. However, it is acknowledged that individuals may have been unemployed prior to their diagnosis of being HIV infected.

Overall, living alone and having a professional status was associated with attending a private physician. These individuals reported more visits to same, (5.5 times greater) than those whose main source of medical care was a Sexual Health Clinic.

Increasing symptom intensity, as demonstrated by developing symptoms since the previous visit, increased the frequency of visits to a medical practitioner. Those persons whose usual source of medical help was their GP / private physician, had significantly more outpatient (specialist) visits than those persons whose usual source of medical care was a Sexual Health Clinic ($p < 0.05$). Retinitis was significant in determining attendance at emergency departments ($p < 0.01$) for individuals with AIDS.

Time since diagnosis was a strong predictor of clinic and GP use. Three years and more since diagnosis, meant that those individuals used SHC and GP services more frequently ($p < 0.05$). Those persons who were clinically defined as having AIDS reported the most visits to the doctor or clinic ($p < 0.05$).

The profile of an HIV positive gay man who was symptomatic, demonstrated disease management occurring on a regular out-patient /clinic basis. AZT and Acyclovir were prescribed in conjunction with Bactrim. General practitioner use was usually in order to attend for non-HIV symptoms. In a twelve month period the total number of visits to an out-patient department would be not less than seven, to a SHC not less than four and to a GP no less than two visits would occur. Inpatient stays were unusual for this group of individuals, a maximum of one per annum for a period of 4.9 days on average ($n=22$).

However, the profile for an IDU who was also symptomatic was very different, there was a mixture of inpatient and outpatient visits. The inpatient stays for this group were related more to the problems of being an IDU, rather than being HIV infected. Indeed, it appeared that hospital admissions for this group and indeed, all hospital/clinic and gp attendances, were instigated **because** of problems related to intravenous drug use. AZT, acyclovir, diverse antibiotic therapy and drugs such as Librium were prescribed. The mixture of services and inpatient stays, averaging seventeen days with not less than two stays over a twelve month period, may appear greater than the others due to the small numbers (n=4) who fall into this category of being HIV infected with symptoms. The number of outpatient visits averaged 23 per annum, with not less than six visits to SHC clinics in conjunction with seventeen visits to their GP. The two respondents with haemophilia demonstrated a greater number of outpatient visits (19 on average, n=2) and inpatient stays than the others who were in the symptomatic HIV group. Inpatient stays lasted three days on average but they experienced 4.5 admissions per annum, interestingly all the hospital admissions were on an emergency basis. This group also appeared to seek medical care due to their pre-existing condition rather than as a direct result of HIV infection. Neither of these respondents attended a SHC for care, community care was from their general practitioner, averaging eleven visits per annum. The numbers may be inflated due to the small number of haemophiliac respondents. Individuals who were asymptomatic (n=87) with SHC/GP visits combined, on average attended 4.8 times per annum at their preferred care site. However, this group attended for psychological counselling (on a private basis, 86.4%) which meant that a substantial number of respondents were paying to have counselling sessions. This is an example of a cost being borne by respondents and one which in a normal style of data collection would not be easily demonstrated. It is recognised that this is a patient choice and one which these individuals choose to bear and feel that they are able to undertake.

AIDS patients (n=91) demonstrated a very different pattern of health care usage. In-patient admissions were, as expected, strongly related to reported symptoms and/or new

symptoms. The appearance of new symptoms increased the odds of a hospital admission (OR= 2.3). People with an AIDS diagnosis were four (4) times more likely to be hospitalised than those without an AIDS label. This is not surprising given the increasing likelihood of greater frailty and increasing complexity of the disease for those persons with AIDS. Individuals who had Burkett's lymphoma and/or Kaposi's sarcoma had frequent hospital admissions for chemotherapy, radiotherapy and immunotherapy. Individuals with PCP (n=62) were likely to be admitted as a result of an emergency admission (OR=4.4). There appeared to be three distinct stages of AIDS. Initially, there was the stage of being diagnosed with one of the twenty-nine CDC (1992) classified AIDS defining diseases. Then there was the stage of coping and living with recurrent and increasing numbers of infections. This stage appeared to cover a period of three and a half years for members of this study group. The final (terminal) stage was when individuals not only had an AIDS defining condition but multiple, severe complications such as respiratory failure, AIDS dementia and CMV retinitis on top of an initial disease such as PCP. For the eighteen individuals in this study who died, the average length of time from development of two or more infections in addition to their initial infection, until eventual death was 6.5 months. Only two individuals died away from home, one in a hospice and the other in a hospital. During the terminal phase (average time 15 days) the use of GP and community nursing services was of a high intensity, averaging one GP visit every second day and community nurses at least twice per day. On the whole AIDS patients average number of visits per site, per annum was as follows: outpatient departments equalled 14.2 ; SHC: 5.2 ; GP:16.5 and inpatient stays: 2, duration 9.4 days.

Interestingly, individuals reported not seeking medical assistance each time they had experienced symptoms. This was significant ($P<0.05$) for those individuals whose main source of medical care was an SHC, a possible explanation of this factor could be explained as accessibility to the medical care site. Finally it was noted that frequency of attendance was not essentially linked to severity of symptoms as a determinant of health service use.

The severity of symptoms experienced by an individual was a determining factor in the level of health services used. This is discussed in more detail in chapter eight.

Home nursing services were utilised by 52% of all respondents, the length of time ranged from 1 day through to 47.5 days; suffering from AIDS, PCP, and /or severe multiple infection was significantly associated with use of the home nursing service ($P<0.05$).

The community mental health team was used significantly ($P<0.05$) more frequently by individuals who had retinitis and who had AIDS. Time since diagnosis being less than 6 months was directly correlated ($r=0.79$) with use of the community mental health team. It is surmised that this is a period when some individuals experience a high level of personal distress on coming to terms with what is in effect the diagnosis of having a fatal disease. It was also directly correlated for individuals who had retinitis ($r=0.91$). Six individuals with retinitis were severely vision impaired and were registered blind. The loss and impairment of a sense, such as sight, would be for many a very distressing event. There were no other significant results.

ALTERNATIVE THERAPIES

The majority (88%) of individuals reported using some form of alternative therapy. The most commonly named were as follows:

Table 7.9 Sources of Alternative therapy used by respondents.

Source of alternative Therapy	Number of respondents
Diet (herbal) therapist	19
Chinese herbal Medicine	32
Accunpuncture	41
Massage (Swedish & Shiatsu)	108
Naturopath	117
Aromatherapy	129

Other therapies mentioned included Reiki, use of crystals, meditation, creative visualisation, yoga, music therapy and hypnotherapy. It is recognised that some of these practices are not necessarily viewed as being therapeutic, but rather they are life style choices. Interestingly, some 68% of respondents mentioned "going to the gym" and general measures of good health being taken. Changing to a vegetarian diet was significant ($p < 0.01$) for 34% of respondents, however, it is unknown whether this change was maintained over time. The use of Kombucha tea was mentioned by 43% of respondents. Interestingly, 68% of respondents who went to a naturopath reported taking extract of "slippery elm". The amount and severity of the symptoms experienced by an individual was significant in the use of massage as an alternative therapy ($P < .0.01$). Time since diagnosis was not a significant factor.

Three respondents travelled to Melbourne to a "Biocentre". There they stayed for periods of time ranging from two -five weeks. They reported receiving "intravenous vitamin C and injections of vitamin B" in conjunction with diet assessment and general health assessments. One respondent travelled to Lyons in France, where he consulted a herbalist and underwent "extensive overhauls" of his diet and lifestyle. Upon his return he was taking extract of "boxwood". The efficacy of these and other treatments are unknown .

Use of an alternative therapy was not exclusive, respondents used a combination approach. There was no difference in use regardless of site of bio-medical care. However, there was a greater likelihood that the individual would be employed. This is not surprising given the cost of the alternative therapies. There were no other significant results.

Distribution of Cases by AN-DRGs.

For ease of comparison the subjects in this study were assigned to the AN-DRG (v2) classification. The detailed definitions of principal diagnosis and principal procedure were taken from the AN-DRG definitions manual (1992).

The table (7.10) following shows the distribution of HIV/AIDS cases by DRG for 1990/91, as described by Palmer et al (1991), as compared with the distribution of cases in this sample. It should be noted that access to clinical notes was not obtained and classification has been carried out on the **reported** reasons for hospitalisation. It is recognised that this may compound errors, however, it is useful in order to identify trends.

Table 7:10 Distribution of HIV/ AIDS Cases by AN-DRG: The Sample Compared to NSW 1990/91 Figures.

<u>DRG</u>	<u>Sample</u>		<u>NSW*</u>	
	No of Cases	(%)	No of Cases	(%)
801	7	4.2	127	4.4
802	28	19.7	240	8.3
803	52	36.6	1659	57.4
804	39	27.5	491	17.0
806	16	11.3	338	11.7
Totals	142	100	2889	100

* as per Palmer et al (1993) utilising 1990/91 figures.

It should be noted that those pooled data account for the number of hospital inpatient stays over the study period. Individual people may be counted more than once depending upon their number of hospital admissions. Similar to the pilot study it was noted that individuals changed from group to group depending upon their diagnosis. This may be due to the fact that this is a prospective study and therefore, the classification of the individual will change over time as the disease progresses. In most DRG classifications the segregation of the

episodes for the individual are carried out retrospectively and hence an individual is assigned to a group on principal and secondary diagnosis. It is argued in this case that individuals will over time change from group to group, as their secondary diagnosis changes, and therefore the case-mix and the intensity will be constantly fluctuating. The principal diagnosis of HIV/AIDS remains unchanged, but the secondary diagnosis/episode changes. The acute episode necessitates the change in DRG grouping with time. It is apparent that the pattern of distribution through the DRG groupings is largely similar in the study to the pattern exhibited in the NSW study. Variations can be accounted for by differences in classifications.

DRG 803, *HIV, related infection, age>9* and DRG 804 *HIV with other Related Condition* accounts for the majority of study respondents. In DRG 803 *pneumocytosis* was the most frequent diagnosis with some respondents being admitted with septicaemia and in DRG 804 anaemia was the most common diagnosis. DRG 802 encapsulated individuals who had Kaposi's sarcoma or Burkett's lymphoma. DRG 806 was those persons in the later stages of the disease. The principal diagnosis for most of the patients in this DRG is either *AIDS unspecified* or *HIV unspecified*.

It is apparent that in the 24 month period people did not remain within a single category. The movement over time can be accounted for by those persons who developed differing conditions in the later stages of the disease and demonstrates the increase in severity of symptoms as individuals graduate into the categories of 804 *HIV with other Related Condition*, which in the main encapsulates those people with unspecified anaemia and DRG 806 *HIV without specified Related condition, age>9*. DRG 806 in the main study encapsulated people in the terminal stages of AIDS.

LENGTH OF STAY

It must be stipulated at the outset that the respondents attended a variety of hospitals in the Illawarra, Sydney, Newcastle and Melbourne areas. It is recognised that the length of stay may vary due to the procedures and treatments employed. There is significant variation in the length of stay across the DRGs, with DRG 806 having the longest length of stay of 16 days, with DRG 804 having the shortest length of stay of 4 days.

Table 7:11 HIV-DRG Average Length of Stay (ALOS) (in days).

<u>DRG</u>	<u>ALOS</u>
801	6.1
802	8.2
803	4.2
804	4.0
806	9.4

Day cases were not included in these figures.

Due to the small number, the average length of stay by DRG will be skewed by an individual's results and therefore, these figures are indicative of a general trend rather than being specific. It must be remembered that results are those reported by individuals and may be subject to reporting and memory bias.

DAY ONLY CASES

There were 263 episodes of reported "day only" cases in the study.

The DRG with the highest proportion of day only cases was DRG 803, *HIV related infection , age>9* which accounted for 70% of reported day cases. The other 30% of cases

were spread throughout the various DRG classes. The main reported sites for care were diverse and were as follows:

Shoalhaven Hospital, Wollongong Campus, Royal Prince Alfred Hospital, Albion Street Clinic, St Vincent's Hospital, Taylor Square Clinic, Prince Henry Hospital, St George's Hospital, John Hunter Hospital Newcastle, Fairfield Hospital Melbourne, Royal North Shore Hospital.

It is recognised that there may have been additional episodes of "day only" episodes, but these may have been reported as specialist or outpatient visits. Information on this particular area was a weak part of the data collected in the study. There was difficulty in verifying whether a case was truly a day only case or whether it was really a visit to a specialist for further consultation. It was not possible to verify data, as the author had no knowledge as to the identity of the GPs, in order to elicit further information. It would also be essential for participants to have given consent to access records at any site. The diversity of sites where care took place would have made accessing data problematic. Individuals were reluctant to give consent for two reasons. Firstly, they feared a loss of confidentiality and secondly, the name that they used in the study was not necessarily the one by which they were known at their doctor/ clinic site.

INPATIENT DRG COSTS.

The costs relate only to the inpatient stay and are based upon the DRG costs estimated by Palmer et al (1993). During the study, there were a total of 142 inpatient episodes. An interesting feature of these episodes is that at the pilot data collection stage, there were fewer episodes with a shorter average length of stay compared to the follow-up, when the number of inpatient stays had increased as had the length of stay. This is a pattern which was monitored during the main study. During the main study no such trend was found. It was noted that the length of stay in DRG 803 in the main study was 4.2 days on average whilst it had been 9.4 in the pilot study. This can be accounted for by an increased use of drug prophylaxis for individuals with PCP. Interestingly, there was an increase in the length of

stay for individuals in DRG 806, this difference can be explained by the inclusion of a greater number of AIDS patients who had longer periods of hospitalisation.

The following costs are recognised as being indicative of a trend, rather than absolutes. During the course of study it became apparent that the use of DRG costs was limiting as it only covered hospital costs. As more and more care is delivered in the community it seems necessary to commence costing from the point of diagnosis and to be inclusive of community care. However, in this instance, obtaining figures from the various sources proved an impossible and a non-productive exercise, and hence yet again there was the recourse to the figures produced by Palmer et al (1993). It is recognised that the work by Palmer et al was undertaken in 1990/1(published in 1993) and the costs may have changed within the time frame.

In the Palmer et al (1993:24) study, it was noted that "the average cost per discharge in the seven teaching hospitals was \$3214". The authors recognised that this figure would not remain constant; they postulated that there would be a number of reasons for change in the costs as follows:

- an increase in the size of funds available;
- a change in the number of total discharges over the period.

Palmer and colleagues (1993), based on the average cost per discharge, calculated a price per HIV/DRG, using HIV/DRG cost weights. They calculated that if a cost weight of 1.00 has a price of \$3214, then HIV/DRGs would have the following prices:

DRG 801	<i>Related Central Nervous System Disease</i>	\$6910
802	<i>HIV Related Malignancy</i>	\$5560
803	<i>HIV Related Infection</i>	\$4339
804	<i>HIV with other Related Condition</i>	\$3053
806	<i>HIV without Specified Related Condition</i>	\$2764

Table 7.12 following, demonstrates the general costs of in-patient care utilising the cost weights as described by Palmer et al (1993). It is recognised that the costs in hospitals out of the state of New South Wales may be different for a variety of reasons such as different treatment protocols and a different philosophy of care. However, in order to gauge a trend the costs have been estimated.

Table 7:12: Cost of Inpatient care using HIV /DRG cost weights as per Palmer et al (1993).

<u>DRG</u>	<u>No of Cases</u>	<u>Price per HIV/DRG</u>	<u>Total (\$)</u>
801	7	6910	48,370
802	28	5560	15,5680
803	52	4339	22,5628
804	39	3053	11,9067
806	16	2764	44,2240
Totals	<u>142</u>		<u>5,929690*</u>

* this figure is the costs for the final groupings at the end of the study and incorporates all episodes during the study period March 1992 until March 1995. The cost is only indicative of trend and cannot be viewed as an absolute.

CLINIC, DAY ONLY AND SPECIALIST VISITS -THE COSTS

It proved to be immensely difficult to obtain figures relating to ambulatory costs. This is in part due to the diverse number of sites from which individuals in this study receive care.

The cost of community nursing services for both general care and mental health are also difficult to discern as the costs are involved and complex in their construction. For example the costs of community care would have to incorporate such items as: the costs of specialist nursing care, travelling time on behalf of the community nurse, supply costs, time spent per visit and the levels of complexity of care involved, that is the activities undertaken at each

site by a particular grade of nurse would also have to be incorporated. It is recognised that this is a significant cost involved, particularly in relation to DRG 806 which includes those individuals who have an AIDS diagnosis and are in need of palliative care in their home, which is an increasing trend. In order to estimate community care costs fully there would have to be an incorporation of: GP costs, community nursing care costs, the cost of specialist home care nurse, such as the palliative care nurse, and for other services such as physiotherapy and the cost of equipment used. Due to the complexity of data required it would not be possible to discern actual costs, but it should be possible to demonstrate a trend towards cost expenditure in the area of HIV/AIDS, through a description of services being utilised by people with HIV/AIDS. In this study the increasing trend towards community /home based care suggests that community care costs are substantial and complex. As previously suggested, if a series of costs were devised it would be possible to incorporate community and psychological care costs.

THE USE OF VOLUNTARY SERVICES.

All the respondents who experienced symptoms ($n=205$) had used some form of voluntary service during the study. The main sources were the Community Service Network and the Anakali project volunteers, both of these services provide "hands -on" support. The range of time was from 1 day through to 68 days. Similar to the pilot study there was a direct correlation ($r=0.92$) between living alone and use of the Community Service Network (CSN) and /or Anakali, during times of symptom exacerbation. No other group exhibited such continual use of the CSN/Anakali projects, for a period greater than 11 days, as did those who lived alone. The average length of time for which people used the volunteer networks was 15.5 days. People with personal carers did use the volunteer system less, but this may also be reflection of management of the networks where priority is given to those people who live alone. Living alone and having an AIDS diagnosis were both significant factors in the use of voluntary services ($p<0.05$). It is recognised that this result could have significance for future use of voluntary services as 51.7% of respondents in the study lived

alone. Individuals with retinitis were heavy users of all voluntary services, utilising all services mentioned and the Royal Blind Society, who were instrumental in the provision of aids and equipment for fourteen respondents.

Meals-on wheels was the second most frequently named organisation, with 85% of respondents stating that they had used their services at some point in the study period. The range of time was from 2 days through to 172 days (and still ongoing).

The community transport system was utilised by 49% of respondents, exclusively for transport to GP, SHC and hospital appointments. AIDS patients were the most frequent users of this service.

The support given by friends and family members was also mentioned by respondents. Thirty percent of respondents stated that they could not live at home without the constant support of their families, as one respondent commented:

"I know they are not volunteers but without family and friends, as well as the volunteer support I would not be able to live at home. It's not possible to put a time estimate on their help and support . But without them I would use the volunteer groups all the time" (31 year old lives alone, HIV symptomatic).

It is recognised that without personal support networks there would be an even greater use of community and hospital services. There seems to be a need for an estimate of services not used due to personal networks. As many of the carers are themselves HIV infected, this group cannot be viewed as an infinite resource. The personal costs of the carers should be taken into account when costs are being estimated. The use loss of employment and premature morbidity are personal costs which need to be further evaluated, but their significance is acknowledged. There were no other significant results.

SERVICE NEEDS.

The respondents were asked what they perceived as the current shortfalls in the services provided. There was a unanimous response in regard to the need for the provision of the following:

- a dedicated counselling (24 hour) service staffed by trained counsellors and psychologists.
- provision of "out of hours" weekend and evening medical services which have specialist knowledge of HIV needs.
- provision of housing at a reasonable cost and easier access to financial benefits.
- less time delays in drugs being approved for use in Australia.
- provision of terminal care within the home.
- provision of an "intravenous service" to stop travel to hospitals.

The need for increased public awareness of HIV and "how you catch it" was mentioned by 35% of respondents. It was interesting to note that some 78% of respondents mentioned the need for increased medical and nurse education. Respondents made it very clear that they were satisfied with the care and attention that they received from their usual source of medical help, whether that be the SHC or their GP, or a combination. They were dissatisfied with the levels of acceptance and general care which they received in the hospital system. It is recognised that individuals who are HIV infected may be more sensitive to the reactions of others because of their own feelings of insecurity. The comments following serve to illustrate this point:

"The outpatient department is like a bee hive, everybody is buzzing around. I feel that I am very low on the priority list" (31 years old, lives with lover, HIV symptomatic).

"I feel like some sort of strange specimen, a bit like a funnelweb, people are curious but don't want to get close" (43 years old, lives alone, has AIDS).

There was no difference in the views expressed and the sources of medical care. It is notable that the respondents were loyal to their main source of care. This was demonstrated when, following the pilot study, there was a change in medical staff at the SHC in Wollongong. Patients followed one particular doctor to Sydney. Reasons for this included feeling comfortable and having built up a trusting relationship with the doctor in question. However, when it came to attending hospitals and specialists there appeared to be a high level of mobility. Reasons given centred upon the perceived attitudes of some specialists. This is illustrated by the following comments:

"Dr X may be really good in his field but his personal manner is appalling. Arrogant, abrupt and condescending. I'm never going back to see him. After a visit I am exhausted, due entirely to anger" (36 years old, professional, lives alone, HIV symptomatic).

"The specialists seem to think they are God, if you ask them a question its like you've committed a mortal sin" (47 years old, AIDS patient, lives with lover).

Compounding the perceived attitudes was the feeling of being specimen being passed around (mentioned by 69% of respondents). Individuals seemed to feel powerless once they entered the domain of hospitals. This coupled with perceived negative attitudes increased the chances of choosing to go to another source of medical help for 47 % of all respondents.

The need for appropriate housing and adequate financial benefits were also mentioned by 78% of the respondents. As two respondents said:

"I've been evicted formally and informally six times in the last nine months, being on the housing list is unhelpful until I get sicker then I'll go on the priority list" (39 years old, HIV symptomatic, lives in shared accommodation).

"If I leave work due to ill-health my quality of life will suffer. I would be really distressed at having to struggle to cope to maintain my lifestyle. Not that I live the life of a high roller, but from my understanding the benefit system only comes into effect once you are really sick" (29 years old, HIV symptomatic, lives alone).

Finally, individuals with AIDS all commented upon their need for a service of home care that would reduce their need to attend clinics and hospitals. This would impact upon the use of the community transport system which is currently used mainly by people with AIDS. In the main these opinions support the comments and opinions of the care providers at SHCs regarding the needs of people with HIV.

Chapter 8: Discussion and Conclusion.

8:1 Discussion of the results of the study.

This study provides new data in a number of areas. First, most studies have described the use of hospital services for AIDS patients, but they have not addressed the other stages of HIV infection nor have they addressed the use of non hospital services. Second, this study has identified that there are differing levels of HIV/AIDS infection and the classifications of these levels has the potential to be developed further, in order to predict care needs and resource consumption. Third, this study has demonstrated that mobility of patients is a crucial factor in the access of and use of health services. Fourth, it has demonstrated that the use of health services varies at the different stages of the disease process and that pre-existing conditions such as being an intravenous drug user appear to impact on the duration and type of care used. It appears that the bulk of care is carried out in the community with a heavy reliance on voluntary and informal carers.

Although the numbers of HIV infected participants was relatively small (n=292) the demographic profile of the sample were representative of the currently infected population in the New South Wales area and of the Sydney region in particular (McDonald et al 1994).

This study identified ten levels of severity which indicated care use and need. From the longitudinal data it appears that there are defined stages of disease through which individuals progress, from diagnosis to death. In the long term it would seem appropriate to cost care needs/ requirements at each stage of the disease, incorporating both hospital and community care. It was apparent that there were differing presentations of AIDS defining diseases, therefore it would be useful to identify these differing presentations in order that needs and costs can be more fully described. Table 8.1 following is a descriptive model based upon the data presented by this study group. Due to the small numbers available, the problems

with self-reporting bias and the inability to triangulate the data by accessing medical records, this is a descriptive model .

Table 8.1 Descriptive Indicators of Disease Progression and Healthcare Use /Need.

Level	Disease stage	Indicators	Healthcare Use/Need
1	HIV diagnosed	Time since diagnosis <6months, GHQ score >8.	Counselling, psychological support, monitoring of CD4 counts,monitoring of psychological state.
2	HIV asymptomatic	Time since diagnosis <3years, CD4 counts in normal range (500-1000).	Prophylactic drug therapy, CD4 monitoring
3	HIV symptomatic	a.CD4 counts, below normal range b.Time since diagnosis >3 years c. Drug related anaemia	a1. AZT therapy+ other prophylactic therapy, psychological support. Treatment of anaemia requiring inpatient stay. CD4 monitoring
4		a(+/-)b/c+ development of symptoms with no apparent "other cause" eg. generalised pain in joints, mouth ulcers, skin disorders	a2. treatment of "other" symptoms +a1

Table 8.1 continued

5		a+two or more non specific symptomsTreatment of symptoms, especially combination of recurrent especially pain therapy +a1 mouth ulcers, pain in joints, +a2+psychological support abdomen &persistent headache, fatigue, psoriasis.
6	AIDS (Diagnosis)	d Diagnosis with an AIDS defining d1.CD4 monitoring, disease, but with no complications. drug therapy, radiotherapy, Disease categories include-oral chemotherapy, candidas, KS with no nutritional therapy, complications & psychological support wasting syndrome
7	Mid -range	Time since diagnosis with an AIDS as per d1. defining disease=3.5 years. d.+Herpes with oral thrush, or wasting syndrome +oral thrush, CD4 <200
8		PCP +KS as per d1
9		PCP+retinitis or disseminated as per d1. For those with Herpes +retinitis or KS retinitis, assistance from the Royal Blind Society with aids for daily living

10	Terminal->Death	Burkett's lymphoma+CMV colitis+ multiple infection/symptoms	as per d1+ palliative care, preferably at home
		PCP+ CMV+ generalised symptoms eg fatigue, anaemia,	Hospice care if wanted by patient or community palliative care.
		PCP+septicaemia+CMV retinitis and/or colitis	

It should be noted that these are descriptive stages from limited data sources. It is known from the literature (Lindback et al ,1994) that individuals who present with a "flu like" illness progress more rapidly to AIDS. In this study, time since diagnosis was used, since it was unknown for those who developed or had AIDS whether they had had a "flu -like illness",which would predict a more rapid progression to AIDS. People who live alone are more likely at any stage to be hospitalised (p<0.05), than those with support mechanisms. The levels or severity of illness outlined are not dependant upon the frequency of visits to a care site. It is argued that frequency may not be an indicator of use or need. The severity of the symptoms experienced is not dependant upon the frequency of visits. Frequency of use is correlated with social factors, such as living alone and using a general practitioner as the central care provider. At any stage an individual can enter a level of severity provided they meet the criteria. The care requirements set out on the table are the minimum requirements of an individual at that particular level.

It can be seen that most care could be delivered in the community setting with hospitalisation for acute episodes. Pre-existing but contributory conditions such as being an IDU or haemophiliac, were not included in this table, as the numbers were too small to give any indication of trend and, during the period of study, their need for care was related to their pre-existing conditions.

The relative frequency of diseases associated with HIV infection, from diagnosis to death, have been characterised previously in a variety of contexts (Greenberg et al 1992; Munoz et al 1993; Rutherford et al, 1990). The findings of this study are in agreement with these published reports. It is now clear that the spectrum of HIV associated diseases varies at different stages of HIV infection and is similar to that reported by Greenberg et al (1992). The first two phases of Symptomatic and Asymptomatic HIV infection were described by Beck et al (1993). However, the authors of that study did not describe the other stages of being HIV infected leading up to the development of an AIDS defining disease and they only described the use of hospital services. The study by Beck et al (1994) demonstrated that individuals with symptomatic HIV used outpatient services more frequently than asymptomatic individuals. This result was replicated in this study. The use of emergency services increased as individuals experienced symptoms; this result is substantiated by the work of Johnson et al (1993) and Beck et al (1993). Whilst not demonstrated in this present study, the work by Lindback et al (1994) suggests that at the point of sero-conversion, evidence of a "flu-like" illness will predict an accelerated progression to AIDS and HIV related diseases. Therefore, it would seem that if data were available from the point of sero-conversion (this could be added retrospectively), the Asymptomatic HIV stage could be broken down into two stages: those who developed symptoms at sero-conversion and those who did not. This would enable further prediction of healthcare use. While the early treatment asymptomatic HIV infected individuals with anti-viral agents is currently controversial (Volberding et al 1990; Abouker & Swart, 1993) and not deemed cost effective (Oddone et al 1993). It appears from the data in this study that anti-viral agents have continued to be prescribed early in the course of HIV infection. This prescribing pattern may be the result of professional caution, understandable in the light of the controversy surrounding drugs such as AZT. Alternatively, the prescription of anti-viral drugs may be linked to individual pressure and choice on the part of the HIV infected individuals. Although asymptomatic, these individuals are utilising healthcare resources and attend outpatient clinics, SHCs and/or their general practitioner for monitoring. This also

results in a cost to the individual with potentially lost employment time, travel and personal (emotional) costs.

During the Symptomatic stage of HIV infection, individuals demonstrated an increased use of hospital and healthcare services, this is substantiated by the work of Beck et al (1994) and Johnson et al (1993). The appearance of drug related disorders such as anaemia result in hospitalisation (Pinching, 1991). It appears that the appearance of new symptoms is a predictor of seeking healthcare. In levels three through to five as noted in this study, the presence of multiple symptoms which result in general discomfort and pain is of importance. Adler (1987) noted that the frequent occurrence of symptoms (such as pain, cough and diarrhoea) are open to treatment and stresses the need for palliative therapy for individuals. The number of pain medications reportedly consumed by study respondents does suggest that there is a need for management of these symptoms. Alternative (prescribed) pain relief medications may be more appropriate for individuals. Proactive management of individuals in the symptomatic stage of HIV infection may result in improved quality of life and a decrease, over time, in the need for emergency admissions.

The final stage of AIDS appeared to comprise three phases. Initially, there was the stage of having acquired an AIDS defining disease as defined by the CDC (1987, 1992), but the individual did not have any other complications. The middle stage was the progression to having complications and often the appearance of another opportunistic infection. The final (terminal) phase was the existence of multiple infections. In this study the time frame from the development of multiple infections to death was six and half months. The study by Markson et al (1994) of the retrospective patterns of expenditure following AIDS diagnosis identified four stages of AIDS and noted that the time between development of multiple symptoms and death was three months. Differences between the Markson et al (1994) and this study can be accounted for by methodological differences. The Markson et al (1994) study was an audit of American hospital admissions and contained a large number of participants. However, in this present study it was not the case that the individual with

AIDS would be hospitalised, most remained at home and hence the possible explanation for the longer period of time prior to death. Individuals are more likely to be admitted to hospital in acute phases and for a variety of reasons such as having no care available. Based on information for this small number of participants, the approach of subdividing the AIDS category into three different levels recognises the diversity and multiplicity of clinical complications typical of disease progression in people with AIDS. According to the work of Beck et al (1993) each different opportunistic infection and tumour, has a different disease course resulting in different patterns and durations of follow-up and thus generates different demands on resources. The small data pool in this study was able to differentiate levels of healthcare use for individuals with and AIDS diagnosis. The group had a (level 10) terminal diagnosis, that is they exhibited a severe AIDS defining diagnosis with a complication such as CMV, had intense demands for healthcare over a relatively short period of time (on average six and a half months). This has major implications for the resourcing of healthcare for individuals in the terminal phase of AIDS. It would appear that those in the late stages of the disease, in the terminal phase had intense resource demands, albeit for a relatively short time. Previous studies, such as the work by Benjamin (1988) in the care of the elderly and Tramarin et al (1992) on home care assistance for people with AIDS, have demonstrated that home care is cost effective at a low level of physical disability. The study by Tramarin et al (1992), demonstrated that an integrated model of care (inpatient, outpatient and home care) was effective only if strict screening criteria to gain access to community palliative care were adhered to. In addition to these criteria, the authors of this study noted that it was essential, that as well as formal community care, there was the provision of family or other support networks. The presence of family or other support networks at any stage of the disease appeared to reduce the need for inpatient care. This is substantiated in the literature by the work of Beck et al (1993) and Tramarin et al (1992). Utilising the levels of severity as described in this present study, specific case management programmes could be developed to the initial severity of illness of the patient population and hence resource use could be matched more effectively to resource need. An important point arises when individuals do not seek care for their medical conditions then it is not possible to assess the

severity of these conditions. It is known from this study that patients do not seek care at every appearance of symptoms, consequently some levels of severity may not have been recorded. However, it is surmised that people are unlikely to ignore the symptoms of most conditions in the last five levels of severity described, especially in the last three levels. It is argued that by classifying people by the severity of their clinical complications, cases could be prospectively followed in order to monitor expenditure, drug and healthcare use and to facilitate the development of patient management strategies. As suggested by Scitovsky (1989), the cost of HIV related illness is a 'moving target' and cost measures will require tools that are sensitive to the ever changing presentations of HIV infection. It is argued that a complex disease such as AIDS makes the use of severity levels necessary to account for significant differences in health care delivery, for patients with differing disease related complications.

Healthcare was accessed from a variety of sources and distance did not seem to be a barrier to service access. It was noted that individuals who used a general practitioner as their sole source of care had a more frequent attendance at specialised sites. Social characteristics such as being unemployed, using a GP as a sole source of care and living alone were all predictors of frequent healthcare use. Living alone and having a professional status were associated with attending a private medical practitioner and subsequent frequent specialist referral. The development of symptoms at any stage in the disease process was a predictor of healthcare use. There appeared to be a growing trend towards community care coupled with outpatient attendance. There was the view that the amount of drugs prescribed had also increased but this was not able to be estimated. As one would expect, people with an AIDS diagnosis used the greatest amount of healthcare and had the longest periods of hospitalisation. Hospitalisation was largely the result of complications of opportunistic infections, not the disease itself which is primarily treated as a chronic outpatient condition. It is notable that eighty-seven respondents remained asymptomatic over the period of study. This finding supports the findings by Beck et al (1994) who noted that a significant number of HIV infected individuals will remain asymptomatic for a considerable period of time.

It was not possible on the basis of this study to describe a typical patient. This finding is important because of the use made of figures purporting to represent "the cost of an AIDS case". Not only are such figures likely to be inaccurate, but they are not able to demonstrate the difference in cost at differing stages of the disease. It is argued that an overall average cost may give an entirely misleading account of the potential costs for individuals and groups. The analysis of the economic aspects of AIDS often refers to the costs of the disease: a common distinction is the one in direct versus indirect care costs (Drummond & Davies, 1989). Direct costs occur due to care and treatment of patients with AIDS or in the symptomatic stages of HIV infection, research and prevention. Indirect costs are defined by Drummond and Davies (1989), as the production losses and (lost) opportunity costs occurring due to illness and death. Another useful distinction in the context of the description of costs relates to the division of case related and general programme costs as described by Leidl et al (1992). Case related costs can be attributed to a patient and would include areas such as a stay in hospital and community nursing care, whereas general programme costs refer to general areas and services such as testing. It is argued that to date only case related costs specific to hospital costs have been addressed in a meaningful way. Currently, cost estimates are at best based on fees for services (Leidl et al 1992). The use of DRGs to classify and ultimately cost services for HIV/AIDS patients embodies this approach and is limited for the following reasons:

- DRGs use average costs as detailed by Mooney (1994);
- DRGs are only appropriate for inpatient hospital admissions and do not take account of indirect care provision;
- It appears that the bulk of care provision occurs in the community setting and hence the use of DRGs only reflects of some of the acute episodes of care provision;
- It appears that the case-mix is constantly changing and this will affect the DRG classification.

The data gathered in this study suggest that there is a need for a series of costing measures to be developed which incorporate the following:

- Community nursing costs for each differing stage of the disease with particular attention being paid to specialist nursing services and terminal care costs.
- Severity measures of each of the phases of HIV/AIDS infection.
- General practitioner costs.
- Hospital, specialist and outpatient costs. It is acknowledged that DRGs would form the basis of hospital costs.
- Community and hospital pharmacy costs.
- Indirect care measures, such as testing and social support.
- Information on patient demographics, as in this study it was observed that people who lived alone had a greater use of care services.
- Costs to those with HIV/AIDs in terms of lost opportunity and income costs.

Patient care requirements could be further determined by the combining of factors, such as length of stay and disease specific measures. The incorporation of DRGs into a parallel system of classification is logical given the amount of work that has been undertaken looking at their application and use in Australia. The movement within DRG categories suggests that there is the potential for 'fine tuning' of co-morbidity and complications within each DRG, this is reinforced by the work by Hindle (1995).

Although the use of community services is seen as a positive model of care, there is a common belief that cost savings and improvement in quality of life can be achieved by community care. Tramarin et al (1992) noted that whilst there are positive benefits to this model of care, strict admission criteria were necessary to enable efficient care delivery and it was vital to take note of the socioeconomic status of the individual and their subsequent social support networks. The levels of severity described in this present study in

conjunction with the demographic details of HIV infected persons are seen as being vital components to the process of planning, implementation and costing of healthcare services.

This study demonstrated that a wide range of organisations and care sites were employed in the treatment and support of HIV/AIDS patients. Medical and nursing care comprise only one part of this and there is a cross -integration of formal medical and nursing care with the other services. In particular, the community and volunteer networks such as Anakali and the Community Support Network. The involvement of a wide array of agencies in the provision of care has implications for the level of service provision and cost estimation. The overlapping of social and health care needs of individuals with HIV/AIDS indicates that there is a need to further integrate and develop services which involve different kinds of carers, such as those described by Raphael (1990) and Ronald & Robertson (1992). The need for short -term, non -hospital accomodation for respite and during times of personal crises, was expressed in this study and is substantiated in the literature by the work of Crystal & Jackson (1992). Although as noted by Beck (1994:522) "that there are substantial changes in the nature of service provision". There would appear to be a lack of appropriate and available services . Access to certain types of care for example, alternative therapies, private home/nursing care were restricted by the ability of the individual to pay and in the case of nursing homes the suitability of the services available. It is postulated that for individuals in the terminal stages of AIDS who lack social support mechanisms, nursing home accomdation may be suited to their needs. Unfortunately, the current service provision within that sector is not appropriate to the needs of individuals with HIV/AIDS as there is not the level of skilled staff to meet their needs. Access to service provision was also dependant upon geographical location. It appears that many services are limited to high prevalence areas, this pattern was noted previously in the literature by Goetzenich (1993) as cited by Beck (1994). As people become more frail, their ability to travel to access services will be restricted and the variance in service provision by geographical location will, for some, become problematic. This has particular implications for those individuals who choose to access healthcare services away from their home due to their fear of discrimination

and disclosure. The use of multiple services over a wide geographical area by those with HIV/AIDS demonstrated that issues as diverse as personal fears of breach of confidentiality and disclosure, the inability to freely access appropriate services locally, the view that Sydney was the centre of excellence and the negative attitudes of healthcare personnel all influenced the site of care chosen by individuals.

This study highlighted the challenge of the ordinary necessities of life such as appropriate housing, housekeeping, cooking, laundry and transport. This is substantiated in the literature by the work of Marazzi et al (1994) who argued that these services are vital to an individual with a fatal, debilitating, chronic illness such as HIV/AIDS. In terms of service access and provision, there were two areas of concern which were highlighted from the interviews with service providers. Firstly, there were the problems of co-ordination of care for patients with HIV/AIDS and secondly, there were the problems of referral to specialist and other services.

In general, problems of co-ordination of care appears to be particularly acute between clinics/GPs and community psychiatry teams. However, there were also problems between hospitals, community staff and the plethora of agencies involved in the provision of care. This is not an unusual problem and was highlighted in the literature by the studies carried out by Beedham & Wilson -Barnett (1993) and Moons (1994). It was the opinion of care providers that co-ordination of care took place at an individual level, usually the patient or an informal care giver co-ordinated care. The development of a more structural kind of co-ordination is highly desirable.

The enablement of effective co-ordination and communication between the professional caregivers needs to be a high priority. It appears from the interviews that territorial attitudes are creating a major barrier to effective communication. This in turn will have a 'knock-on' effect in terms of the quality of care provided. Whilst personal networking is commendable, it may mean that some people with HIV/AIDS are unwittingly denied access to certain types

of specialist care. Inadequate communication between professionals could result in duplication of services to patients, potential contra-indicated drug prescribing and a loss of faith and confidence in professional staff by patients. It does not seem unreasonable to argue that part of the reason for patient mobility could be traced to ineffective communication between professionals.

The mobility of patients suggests that needs are not being met within their local area. But it also serves to highlight other issues. People with HIV/AIDS are willing to travel considerable distances to access care. Travelling for care may also be linked to fear of being seen attending a care site that is associated with AIDS care. It was observed that individuals in this study moved with their doctor, to ensure continuity of care with an individual that they knew and trusted. It is surmised that the mobility of patients is strongly associated with a fear of breach of confidentiality and the potential for discrimination. Mobility was also associated with the views expressed by some health professionals. In some cases respondents felt that professional staff demonstrated inappropriate attitudes. It is unknown whether these attitudes were the expression of negative views towards gay men who were HIV infected, or whether these professionals treated everyone in the same manner. It does serve to highlight the need for professional education in the area of communication and in particular, the need for sensitivity when dealing with gay HIV positive men. It is recognised that these comments also highlight the concerns of gay men in relation to the anti-homosexual feelings of doctors (Wadsworth & McCann, 1992) and health care providers in general (Paroski, 1987; Hellman & Stanton, 1989). How individuals perceive healthcare providers does seem to affect decisions made about whether to access care through a particular set of individuals. It was also apparent from the perceptions of respondents that the context in which care delivery takes place is still hampered by fears of being ostracised (Grief & Porembski, 1988) and discrimination (Cotton & Kumari, 1990). In the Australian context this is particularly relevant where a high profile group are still expressing concerns about the way in which they experience the healthcare system. Some

twelve years plus into the epidemic it appears that the issues of stigma and discrimination are still impacting upon healthcare delivery and use.

In terms of psychological support it appeared that there were a wide range of sources used (not all were viewed by care providers as being appropriate). Given the results from the GHQ, it appears that the first six months post diagnosis, the development of symptoms at any time and ill health due to AIDS were all times when individuals reported a level of psychological distress which required intervention. The work by Lubeck and Fries (1992) supports the view that quality of life as perceived as a state of "wellness " declines for HIV infected individuals once symptoms are experienced. Other reported needs for care related to the following:

- Improved levels of community psychiatric support.
- "Out of hours" specialised HIV/AIDS medical and nursing care
- The frequent occurrence of certain signs and symptoms (such as pain) which are amenable to treatment stresses the need for adequate assessment and treatment, if only to reduce the levels of self-medication by patients.
- The provision of a specialised (terminal) care team.

It is postulated that the use of alternative therapies is in part a response to a perceived need and one which is not currently being fulfilled by bio-medical services. It is argued that the use of alternative therapies can be seen as one mechanism by which individuals can have a degree of control over their own treatment. This need for control is confirmed in the literature by the work carried out by Taylor (1983), looking at some of the mechanisms employed by individuals when confronted by a life threatening disease. The levels of alternative dietary therapy employed by respondents does seem to suggest that there is a need for nutritional advice and assistance. Given the levels of alternative therapy employed

it does seem that there is a need to evaluate the efficacy of these treatments. These findings of service need were consistent amongst both staff and patients and have significance for the planning of future services.

Finally, the use of voluntary agencies was significant and it appeared from the comments made that these services were fulfilling a necessary and useful role. However, as noted by Patton (1990), voluntary services exist largely because conventional services are not available nor deemed adequate to meet the needs of the population. It is argued that voluntary support is seen as acceptable to all HIV positive individuals, but to gay men in particular, as it is an area of care provision over which they can have control and those who volunteer are not liable to be judgemental in their attitudes or approach. Patton (1990) noted that many volunteers were themselves HIV infected and hence, the supply is not inexhaustive. Voluntary services cannot be seen as substitutes for statutory services (McCann, 1990), but their use does indicate areas of unmet need in current service provision.

8.2 Limitations of Study

It is important to underline the methodological limitations of this study prior to drawing conclusions. Data on service use were gathered from volunteers who agreed to participate in the study. The sample in this study is best considered a sample of convenience and so vulnerable to volunteer bias. However, two factors argue strongly against a sampling bias explanation. First, volunteers out of necessity were recruited from as wide a range of settings as possible and yet produced a wide range of respondents. Second, there was a spread of demographic characteristics across the sample and individuals were from various strata in society, yet there was heterogeneity on the views and patterns of healthcare access and utilization. Because the sample is a sample of convenience, it was very small (n=292) and was not a randomized sample representative of the total HIV infected population. Therefore, it is important that any generalization be treated cautiously.

Although the majority of respondents were not collected from clinical sites, it cannot be discounted that those more concerned with AIDS and their own condition, would be more motivated to enter the study. However, the range of participants and analysis of demographic variables such as age, socio-economic status and range of HIV infection suggests that the sample was representative of the majority of HIV infected people in Australia. From a statistical perspective, the low frequency of intravenous drug users ($n=4$), haemophiliacs ($n=2$) and those of non-European ethnicity ($n=28$) means that the interrelationships between these and other variables needs cautious interpretation. The problems of self reporting and tailoring replies to the perceived desires of the researcher were known and were seen as a problem. The extent of this is unknown. Interestingly, those individuals, who due to their condition, were experiencing visual problems still managed to complete the study. For one, his partner completed the questionnaire on his behalf, the others telephoned the researcher and gave verbal answers to the questionnaire.

The fact that respondents were not collected solely from clinical sites was a weakness and yet it was also a strength of data collection. The detailing of services accessed was not limited by, or to, specific clinical sites and this, in turn, served to illustrate the mobility of the respondents. The importance of patient migration, if only for clinical services, is a particularly important issue in the planning and costing of healthcare services. Patient migration from and to the study was not considered to be a problem as the data gathered had repeatability and consistency. The trends over time coupled with changing disease status were considered to be of more importance than the retention of specific individuals.

Although the data collection instruments were, with the exception of the GHQ, designed specifically for this study, the data collected was repeatable and consistent over the study period. It is surmised that the longitudinal design of the study countered many of the design issues/problems. Despite the problems of being unable to access clinical notes or identify individuals except by a code or pseudonym, the method was shown to be feasible. Service

use data were successfully derived from the self reporting questionnaire and a picture of care accessed and used by HIV positive and AIDS patients emerged. When these data were viewed in conjunction with the responses of the care providers, it was possible to view the spectrum of care provision and some of the barriers to care delivery and access. Profiles of the care accessed at various stages of the disease illustrated the composition and frequency of care over the spectrum of the disease. The results do demonstrate that a fruitful and comprehensive database could be established by taking this type of approach.

However, the method was idiosyncratic in its approach and implementation. It was time consuming and expensive to undertake in terms of time and effort. The amount of information received was complex and indicative of the plethora of organisations and individuals involved in the provision of care, at various stages of HIV infection. In order to not sanitise the results, as suggested by Seed (1994), it seems in order to detail some of the more difficult parts of the accessing and collecting of data. These issues are important as they reflect the reality of dealing with a heavily researched group.

Accessing the study group proved to be difficult largely due to the number of studies which have been, and continue to be, carried out with the HIV population. There was also a sense of "client protection" by professional staff. Whilst this is commendable, it proved to be a considerable barrier. Interestingly, staff themselves were also reluctant to take part in the study, they also seemed to be feeling the effects of being previously investigated.

Confidentiality as described by Allmark (1995) was a barrier to access. It was only after numerous reassurances, that individuals and care sites would not be identified, that some reluctantly agreed to participate. Once participation was agreed upon the problems of actually undertaking interviews and data collection were brought to the fore. Individuals working in healthcare are busy and a study of this type would be low on their individual priority list. Consequently it took a great deal of perseverance to obtain the interviews. Numerous telephone calls before the actual interview, arranging and confirming the interview, did not guarantee that the interview would take place. After three attempts,

whereby the researcher had travelled to the interview and nothing happened, the potential participant was struck off. Fortunately this only happened twice.

Protection of their own identity, by HIV respondents, was seen as reflecting the need to retain control over their personal privacy. The reasons for this are understood yet they proved to be an intractable barrier and meant that it was not possible to access clinical notes and hence verify data. Accessing HIV infected individuals was a fraught process of personal networking, during which the researcher encountered a wide spectrum of reactions from open hostility to a warm reception. Some respondents did express concerns that as the researcher was a woman, there was the potential for voyeurism and the feeling as previously reported by Miller (1990) that they were being viewed as "exotic deviants". There was a limited amount of personal contact with some respondents and this served to open the way to accessing other HIV infected participants. The very simple measure of having respondents return their questionnaires to a post office box number did much to facilitate replies. There was always the worry that the information reported would not be accurate. However the volume and level of detailed reporting negated these worries. It was also felt that people were genuine, as to take time to complete such a lengthy questionnaire for any other reason would be a strange activity.

The problems of attrition are a constant feature of longitudinal studies (Bailey, 1982) and this was the case in this study. The actual numbers were small and consequently the data are limited, but it was possible to demonstrate that despite the problems it was possible to collect data over a period of time. Ideally, the longitudinal method combined with a retrospective audit, at a series of centres, would enable the collection of data with large numbers of respondents. In that way the levels and types of clinical problems at each stage of the disease could be determined. When studying complex diseases such as HIV/AIDS, it seems necessary to account for significant differences in health care need and use, by patients with differing disease -related complications. The complications reported in this study are indicative of trends and potential rather than absolutes due entirely to the small

numbers in the study. It was recognised that individuals, because of the non specific nature of some of the complications and the length of time that they have been coping with them, may have not reported all the complications that they were or had experienced. By combining the self-reporting aspects of the study with retrospective audit a fuller picture would emerge over time.

The complex arena in which this work took place demonstrated the context in which the study took place. This was an environment in which issues such as stigma (Ross ,1994), discrimination and homophobia were still vital (Minichiello, 1992). The extraneous social pressures had the ability to influence the participation, behaviour and response of the participants and the researcher. The extent of these external influences are unknown but their potential to have influenced participation are acknowledged. Despite issues such as stigma, confidentiality and discrimination, the benefits of being able to describe changes over time were seen as outweighing the problems.

The methods of data capture whilst they had inherent problems were seen as appropriate to the study being undertaken. The survey instrument designed for this study had room for improvement. It would with hindsight have been beneficial to have included questions which asked for more background information on issues such as whether the individual was an injecting drug user, sources of prescribed drugs, compliance with drug regimens and detailed specifics about treatment whilst in hospital. However, some of these questions may have been seen as too intrusive by respondents and may not have been answered. All surveys are open to inaccurate recall of events by participants (Sarantakos, 1992), and the inability to undertake data triangulation (Dane, 1990) may have compounded recall bias. However, there is also the need in social research to value and accept that respondents will answer as honestly as they are able to (May, 1993). The opportunity for individuals to express their views on their experiences of healthcare was a rich and consistent source of data and it is argued that the "free space" enabled some data to be captured for which there had not been specific questions. The actual method employed was in essence a reflection of

the need for compromise in order to access and capture data on complex groups of individuals. In many ways this study does as noted by Seed (1995:845) demonstrate that the "idealized cannons as described in the literature are not necessarily useful or translatable in practice." The attempting of a longitudinal study was fraught with logistical problems not least initial access, the tracking of individuals proved to be difficult and the inability to triangulate data was an area which proved to be impossible, due to individuals not giving consent. Whilst the reasons for non-consent were understood it was an area of frustration. The survey method whilst flawed was able to yield useful data, but the accessing of individuals was far from ideal. In many ways it was solely good fortune that individuals came from a wide strata of society. The small number of individuals who noted that they were haemophiliacs or IDUs may not have represented the total number of such individuals who participated in the study. It is recognised that the literature does note that HIV infected IDUs have a greater use of healthcare services (Tramarin et al 1992), however, the numbers in this study were too small to make wide ranging comment on their healthcare use. In retrospect it would have been appropriate to have actively recruited individuals who were HIV infected IDUs. However, it was felt that that they would have been a more difficult group to access due to the extra burden of stigma placed upon them by society (Minichiello, 1992).

The key limitations of this study include: the inability to triangulate data, accessing participants, confidentiality was a barrier to both initial access and further information, researching a heavily researched group and the reliance upon networking as a means of access and study recruitment. The omission of questions regarding previous health status for example, whether a person was an IDU impacted upon the quality of the data collected, especially in the light of the point which stipulates that IDUs have a greater need for and use of health services when HIV infected (Morton et al 1994), although the question remains as to whether individuals would have answered such a question.

8.3 Areas for future research.

The following are suggestions for further research based on the findings of this present study.

The amount and levels of alternative therapy used are substantial. There appears to be a need to ascertain the cost, use and efficacy of alternative therapies, in relation to HIV/AIDS and indeed, in other long-term diseases.

The cost of healthcare needs to be measured from the point of diagnosis through to death. This would necessitate the development of a series of cost measures which would include community care, hospital care and terminal care. Cost measures should be available for each stage and phase of HIV infection. The series approach to costing would be applicable to any other long-term disease.

The need for a co-ordinated approach to care delivery is deemed essential. There requires to be a protocol set in place and then evaluated. The problems of care co-ordination are probably not restricted to HIV/AIDS care. From the literature it appears that the case management system would solve many of the problems with care coordination. Reasons for this system not being adopted in full, given the success in the UK and USA are currently unknown.

There needs to be further investigation, from the time of sero-conversion until death from AIDS, of what constitutes appropriate measures of healthcare need and disease progression. These measures could be used in conjunction with demographic and other information to predict healthcare use.

It would be appropriate to combine a longitudinal approach with a retrospective case note audit, on a multicentre basis, in order to determine and validate predictors of healthcare

needs and use. This approach would be appropriate for any long term disease. It is postulated that there is a significant level of patient mobility in accessing healthcare in any long-term disease. Hence the need for a multi-stage, multi-centre approach.

This study obtained data on the experience of health services as perceived by HIV infected individuals. In this instance the comments given were used to substantiate other findings. It is recognised that this is a rich source of data and an area which requires further research. The narrative analysis of health care experience, such as that begun by Viney & Bousfield (1991) would enable a more sensitive approach to be taken in the delivery of healthcare. Narrative analysis would also be a most effective comment on the quality of services as perceived by the recipients of healthcare.

All research projects answer some questions, but what is left unanswered as a result of the initial investigation means that there is always a need for further research.

8.4 Conclusions.

A number of conclusions, with important implications for the measurement, delivery, and use of healthcare for people with the HIV/AIDS infection, can be made from this study.

1. The study methods were shown to be feasible although the limitations are acknowledged. Service use data were successfully derived and a picture of the care supplied to and accessed by, HIV/AIDS patients emerged.
2. AIDS/HIV patients can be classified by a series of clinical measures, in such a way that their care needs and actual resource consumption can be predicted. Although the numbers of patients in the sample were small, it was possible to identify from the point of diagnosis through to death, indicators which were applicable to the various levels of HIV infection. There are four distinct phases of HIV infection as follows: HIV asymptomatic,

HIV symptomatic, development of an AIDS defining disease then progression of this state to the terminal stage of AIDS. This study has identified ten levels of disease progression with clinical indicators at each stage. The potential health care needs are also described. The model is descriptive in nature and is limited by the small study numbers, the self reporting nature of data collection and the potential that not all symptoms were noted by respondents. The model requires further and wider research to develop it further.

3. Patients with HIV/AIDS are highly mobile in their accessing of healthcare services. Reasons for this mobility include: fear of identified as being HIV infected by attendance at a local clinic; accessing care which has a "good reputation" within informal networks; seeing some sites as being able to supply certain types of care. Patient mobility also indicates patient choice and the meeting of healthcare needs by accessing care from various sites. This is a valid option provided the reasons for choosing different providers are not due to leaving others because of attitudes. Some respondents indicated that they perceived negative attitudes from healthcare providers. It would appear that there may be a need for further and ongoing education of healthcare providers, to enable them to improve communication skills and be more sensitive in their dealings with patients.

4. Co-ordination and referral to healthcare agencies is an idiosyncratic affair, relying upon personal networking and reputations. The co-ordination of care takes place at the individual patient level with the patient and/or the informal carer being the co-ordinator of care. There requires to be a structural approach taken to the co-ordination and referral of health care. This is important as this study has demonstrated that there are a wide number of statutory and voluntary healthcare agencies providing care. This means there is the potential for the over-provision of some services and an under-provision of others. Geographical location also affects the level of service, some inner city suburbs have a high concentration of services whilst outer areas of the city are less endowed. This disparity is important given the views expressed by providers of care about the low levels of access (due in part to cultural views of HIV /AIDS) by people from ethnic minority groups, many of whom live in

the outer suburbs and other areas. The adoption on a wide spread level of a case management system incorporating both hospital and community services as described by Piette et al (1990) and Piette et al (1992) would seem to be a solution in part to the problems of care coordination. It is noted however, that this would require education programmes for health professionals. It would appear from the views expressed by respondents, that the current level of adoption of the case management approach, has had a limited success. It is suggested that a more pro-active approach would enable more effective care provision and coordination of care.

5. Although not wholly conclusive, the trends in this study suggest that unmet healthcare needs include the following:
 - provision of specialist home care services, particularly in the terminal phase of AIDS;
 - the inability to access community psychiatry services easily;
 - the use of alternative therapies, suggesting that current bio-medical services are not meeting needs;
 - the taking of a considerable number of proprietary medications to alleviate symptoms such as pain suggest the need for a review of care, at the palliative stage in particular;
 - the high levels of voluntary services to provide care suggests that statutory services are unable to provide certain types of care;
 - there are difficulties in accessing housing and financial benefits;
 - it was the view of the respondents that there required to be the provision of

short term respite care in a non hospital setting needs to be provided.

6. The costs of HIV/AIDS relate not solely to the provision of care. Costs were identified whose evaluation was beyond the scope of this study. These costs include morbidity, premature mortality, lost income and employment. The trend toward community care coupled with a potential increase in prophylactic drug prescribing means that these costs should be evaluated. The fact that it was not possible to describe a typical patient means that costs must be estimated on the various stages and clinical indications of each of the phases of HIV/AIDS. Any costing mechanism must incorporate community, hospital and indirect care costs. The importance of demographic characteristics in affecting use and costs should not be underestimated. In this study it was demonstrated that living alone, being a professional and attending a private medical practitioner were indicative of higher levels of healthcare use. It seems appropriate to develop a series of cost measures from diagnosis till death. The use of DRGs is helpful but insufficient given the trend towards community care.

The conclusions of this thesis suggest that there is a need for review of current service provision and costing measures.

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Appendices

- 1. Data Elements.
- 2. The Questionnaires.
- 3. The Interview Schedule.

Appendix 1: Data Elements.

Demographic Details.

Age group; Gender; Sexual orientation; Residence; Co-habitation status; Race; Employment status, Marital status.

Current Services used:

Source of medical care; Number of visits in time period; Number of outpatient visits; Inpatient stays; Duration of inpatient stay; DRG classification; Use of alternative therapy; types of alternative therapy.

Non-hospital services used:

Voluntary services: type and duration; Informal carers; counselling; Home care nursing; others.

Clinical status:

Time since diagnosis; symptoms experienced; drugs taken; AIDS diagnosis; radiotherapy; chemotherapy; other.

Service needs:

Categories defined by responses of participants.

Appendix 2: The Questionnaires

Cover letter, questionnaire and consent form.

PART 1: SERVICE NEEDS AND USE.

In the following please tick () the most appropriate response.

1 When did you first learn that you were HIV positive?

- | | | |
|----|-----------------------|-----|
| a. | Less than 1 month ago | () |
| b. | 1-2 months ago | () |
| c. | 3-5 months ago | () |
| d. | 6-11 months ago | () |
| e. | 12-17 months ago | () |
| f. | 18-23 months ago | () |
| g. | 2 years ago | () |
| h. | more than 2 years ago | () |
| i. | unable to remember | () |

2. Have you experienced any symptoms of HIV infection to date?

- a. YES ()
- b. NO ()

If you answered "YES" please detail the symptoms which you have experienced to date.

3 Have you sought medical treatment on every occasion that you have experienced symptoms?

- a. YES ()
- b. NO ()

If you are able please detail the treatment given in relation to the symptoms you were (are) experiencing.

4 Are you currently on drug therapy?

- a. YES ()
- b. NO ()

5 If "YES" from the following list please tick the drugs you are currently taking.

- | | | | | | |
|---|------------------|-----|---|--------------------|-----|
| a | Antibiotics | () | i | Acyclovir | () |
| b | Zivodine(AZT) | () | j | Ganciclovir (DHPG) | () |
| c | ddl | () | k | Anti-fungals | () |
| d | ddC | () | l | TMP-SMX | () |
| e | Methadone | () | m | Dapsone | () |
| f | Imuthiol | () | n | Fansidar | () |
| g | Alpha-interferon | () | o | Rifabutan | () |
| h | Cortico-steroids | () | p | Isonazid | () |

6 If you are taking drugs not listed ,(or if you do not recognise any of the above named drugs) please state which drugs you are currently taking.

7 How long have you been taking drug therapy for, in relation to your most recent infection.?

- | | | |
|---|---------------------|-----|
| a | Less than 1 week | () |
| b | 2 weeks | () |
| c | 3-4 weeks | () |
| d | 1 month | () |
| e | Longer than 1 month | () |
- please state for how long.....

which drugs?.....

8 Have you undergone chemotherapy in the last 6 months?

- | | | |
|---|-----|-----|
| a | YES | () |
| b | NO | () |

9 Do you use any of the following "alternative" therapies?

- | | | |
|---|------------------------------|-----|
| a | Traditional Chinese Medicine | () |
| b | Accupuncture | () |

- | | | |
|---|-------------------------|-----|
| c | Aromatherapy | () |
| d | Shiatsu massage | () |
| e | Hypnotherapy | () |
| f | Autogenic training | () |
| g | Reflexology | () |
| h | Iridology | () |
| i | Other please state..... | |

10 What is your usual source of "traditional" medical / nursing help ?

- a Hospital ()
- b Sexual health clinic ()
- c Family doctor ()
- d AIDS clinic ()
- e Other, please specify.....

11 Which health services have you used in the past 6 months?

- | | | |
|---|------------------------------|-------|
| a | Hospital out-patient dept. | () |
| b | Hospital in -patient care | () |
| c | Home nursing | () |
| d | Aids clinic | () |
| e | Sexual health clinic | () |
| f | Family doctor service | () |
| g | Drug clinic | () |
| h | Community mental health team | () |
| e | Other please state | |

12 Have you used any of the following voluntary services in the past 6 months?

- | | | |
|---|---------------------------------|-------|
| a | Anakali | () |
| b | Community Service Network (CSN) | () |
| c | Meals - on - wheels | () |
| d | Life line | () |
| e | Volunteer carer | () |
| f | Other please state | |

13 If possible you are asked to give the amount of contact time, in the last 6 months, spent in receiving help from health and voluntary services. It would be helpful if you could express the time in units such as days, for example:

Meals-on-wheels =8 days. Eye clinic= 2 days. inpatient stay=6 days.

14 Do you feel that you are given a choice about the health services and treatments offered to you ?

a Yes () b No ()

If you replied "No" please detail which aspects of your care that you feel are devoid of choice.

15 What in your opinion are the shortfalls of the service(s) currently available to you.

16 What services would you like that are not currently available to you ?

PART 3: PERSONAL DETAILS.

Please be assured that all information will be treated with the utmost confidentiality.

In the following you are asked to tick () the most appropriate response.

1. Age range:

- a. 15-19 years ()
- b. 20-24 years ()
- c. 25-29 years ()
- d. 30-34 years ()
- e. 35-39 years ()
- f. 40- 44 years ()
- g. 45-49 years ()
- h. 50-54 years ()
- i. 55- 59 years ()
- j. 60-64 years ()
- k. 65+ years ()

2 Gender:

- a. Male ()
- b. Female ()

3 Sexual Orientation.

- a. Heterosexual ()
- b. Homosexual ()
- c. Bisexual ()

4. Race.

- a. Asian ()
- b. Afro- Carribean ()
- c. Aboriginal/ Torres Strait Islander ()
- d. Caucasian (White) ()
- e African ()
- f Maouri ()

5 What is your current marital status (ie to a woman) ?

- a Single ()
- b. Currently married ()
- c. Separated ()
- d.Divorced ()
- e. Widowed ()
- f. In a "de facto" relationship ()

6 Occupation.....

(Please just state this in general terms eg, Secondary School Teacher, Unemployed, Beneficiary, University Student, Retail Manager).

- 7 Usual place of residence.
- a. Metropolitan (ie Sydney) () b. Urban (ie Wollongong) ()
c. Rural () d. Other(please state).....

- 8 Do you currently live :
- a. Alone ()
b. with parents/ family ()
c. with husband/wife ()
d. with your lover ()
e in a shared property ()
f. with friends ()

- 9 Who knows your HIV status ?
- a. No-one ()
b. Lover only ()
c. Parents only ()
d. Family and Close friends ()
e. All personal contacts ()

- 10 In order to travel to hospital appointments do you use
- a. Own car () b. Public transport ()
c. Volunteer driver () d. Family / Friends car ()

- 11 How long on average does your journey take to hospital/clinic appointments?
- a. Less than 1 hour () b. 2 hours () c. 3 hours ()
d. more than 4 hours () please state journey time.....

If you have any comments, suggestions to make about your healthcare and indeed generally about dealing with being HIV positive, please feel free to do so.

Thank you for your time and cooperation in completing this questionnaire.

The instruments used in the main study: the cover letter, questionnaire and consent form.

Dear Participant,

Thank-you for agreeing to participate in this study looking at the use of health services for people who are HIV positive.

Please complete the enclosed questionnaire, and place it in the sealed envelope when finished. This envelope is stamped in order that your reply will not cost you any money. Please be assured that the envelope and questionnaire will only be seen by me, **no-one** else will have access to this information. There are a total of six questionnaires and return envelopes, please return a completed questionnaire each time you require healthcare.

Some questions will appear to be useful while others may appear to be less relevant. All questions are, however, of importance, and I would ask you to be sure to fill in every question. Because many questions are personal please do not place your name anywhere on these forms. This will ensure confidentiality.

I would like you to fill in a follow-up questionnaire, on your next visit (to your usual source of Health care) in a few months time. A number to identify you will appear at the top of this page. Please keep this number for future reference. It is necessary for me to keep (in a locked file) one master list with

your number, so that all your help will not be wasted by my being unable to match up the questionnaires. If you are uncomfortable with using a number please feel free to place another identifier on the returned questionnaire.

If you feel comfortable in doing so I would appreciate your permission to access your medical records and/or have the opportunity to seek additional information from your clinic or general practitioner. Please complete the enclosed permission slip, which would enable my access. You should be aware that your doctor may also refuse to allow access to medical notes. but prior to contacting your doctor, I would like to have your permission to proceed. **Without your permission no information will be sought from any other sources.**

Should you have any queries about the questionnaire, or the research in general, please do not hesitate to contact me on:

(042) 213327

When the data have been fully analysed, you will be able to get a copy of the results. Alternatively, you are welcome to contact me at that time to find out further information.

Thank- you in anticipation of your help and co-operation.

Maggie Jamieson. Ph.D Student Dept. Public Health and Nutrition
University of Wollongong.

Consent Form.

The measurement of Healthcare need and use for people who are HIV infected from Diagnosis to death.

Maggie Jamieson, Department of Public Health and Nutrition.
University of Wollongong.

This research project is being conducted as part of a Doctor of Philosophy programme, supervised by Professor D Hindle in the department of Public Health and Nutrition at the University of Wollongong.

The purpose is to collect information, about the need for and use of Healthcare, by people who are HIV infected.. For this reason you are asked to complete a questionnaire each time you attend a doctor or hospital seeking treatment for HIV. In addition, if you are willing to allow access to your medical records and general practitioner, this information will be used to support and verify the information collected. You will not be identified, except by a number, or a code of your choice. Your name is only required to enable access to your records. Your name will not be recorded in any format and all questionnaires will be destroyed upon completion of the study. The questionnaire will only be viewed by the researcher.

You are free to withdraw from the research project at any time. In order to participate you do not have to allow access to your GP/medical notes, it is your choice.

This research work has been passed by the University of Wollongong Human Research Ethics Committee, please feel free to contact the secretary on 042-213079.

I understand that the data collected will be used to enhance and verify the information given by me. I consent for the data to be used in that manner.

PART 1: SERVICE NEEDS AND USE.

In the following please tick () the most appropriate response.

1 When did you first learn that you were HIV positive?

- a. Less than 1 month ago ()
- b. 1-5 months ago ()
- c. 6-11months ago ()
- d. 12-17 months ago ()
- e. 18-23months ago ()
- f. 2 years ago ()
- g. more than 2 years ago
but less than 5 years ()
- h. more than 5 years ago ()
- i. unable to remember ()

2. Have you experienced any symptoms of HIV infection to date?

- a. YES ()
- b. NO ()

If you answered "YES" please detail the symptoms which you have experienced to date.

3 Have you sought medical treatment on every occasion that you have experienced symptoms?

- a. YES ()
- b. NO ()

If you are able please detail the treatment given in relation to the symptoms you were (are) experiencing.

4 Are you currently on drug therapy?

- a. YES ()
- b. NO ()

5 If "YES" from the following list please tick the drugs you are currently taking.

a	Antibiotics	()	i	Acyclovir	()
b	Zivodine(AZT)	()	j	Ganciclovir (DHPG)	(.)
c	ddI	()	k	Anti-fungals	(.)
d	dddC	()	l	TMP-SMX	(.)
e	Methadone	()	m	Dapsone	()
f	Imuthiol	()	n	Fansidar	()
g	Alpha-interferon	()	o	Rifabutan	()
h	Cortico-steroids	()	p	Isonazid	()

6 If you are taking drugs not listed ,(or if you do not recognise any of the above named drugs) please state which drugs you are currently taking.

7 How long have you been taking drug therapy for, in relation to your most recent infection.?

a	Less than 1 week	()
b	2 weeks	()
c	3-4 weeks	()
d	1 month	()
e	Longer than 1 month	()

please state for how long.....

which drugs?.....

8 Have you undergone chemotherapy in the last 6 months?

a	YES	()
b	NO	()

9 Do you use any of the following "alternative" therapies?

- a Traditional Chinese Medicine ()
- b Accupuncture ()
- c Aromatherapy ()
- d Shiatsu massage ()
- e Hypnotherapy ()
- f Autogenic training ()
- g Reflexology ()
- h Iridology ()
- i Other please state.....

10 What is your usual source of "traditional" medical / nursing help ?

- a Hospital ()
- b Sexual health clinic ()
- c Family doctor ()
- d AIDS clinic ()
- e Other, please specify.....

11 Which health services have you used in the past 6 months?

- a Hospital out-patient dept. ()
- b Hospital in -patient care ()
- c Home nursing ()
- d AIDS clinic ()
- e Sexual health clinic ()
- f Family doctor service ()
- g Drug clinic ()
- h Community mental health team ()
- e Other please state

12 Have you used any of the following voluntary services in the past 6 months?

- a Anakali ()
- b Community Service Network (CSN) ()
- c Meals - on - wheels ()
- d Life line ()
- e Volunteer carer ()
- f Other please state

13 If possible you are asked to give the amount of contact time, in the last 6 months, spent in receiving help from health and voluntary services. It

would be helpful if you could express the time in units such as days, for example:

Meals-on-wheels =8 days. Eye clinic= 2 days. inpatient stay=6 days.

- 14 Do you feel that you are given a choice about the health services and treatments offered to you ?

a Yes () b No ()

If you replied "No" please detail which aspects of your care that you feel are lacking and over which you feel you have no choice.

- 15 What in your opinion are the shortfalls of the service(s) currently available to you.

- 16 What services would you like that are not currently available to you ?

- 17 Have you been in hospital in the last three/six months?

- 18 Which hospital were you in?

19. Why were you admitted to hospital (if you are unsure please feel free to list the symptoms you were experiencing which caused you to go to Hospital)
20. When you are sick who looks after you?
- 21 Do you always go to the same hospital /clinic each time you are sick?
(If not please detail why you choose to go to other places for care)

GENERAL HEALTH QUESTIONNAIRE

GHQ-28

Please read this carefully:

We would like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank-you very much for your cooperation.

HAVE YOU RECENTLY:

A1 - been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2 - been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 - been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 - felt that you were ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 - been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 - been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 - been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
B1 - lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2 - had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 - felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 - been getting edgy and bad tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 - been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6 - found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual

B7 - been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
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HAVE YOU RECENTLY

C1 - been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2 - been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3 - felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
C4 - been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5 - felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
C6 - felt capable of making descisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7 - been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
D1 - been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2 - felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3 - felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4 - thought of the possibility that you might do away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5 - found at times you couldn't do anything because your nerves were too bad?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D6 - found yourself wishing you were dead and away from it all?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D7 - found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	Has crossed my mind	Definitely have

PART 3: PERSONAL DETAILS.

Please be assured that all information will be treated with the utmost confidentiality.

In the following you are asked to tick () the most appropriate response.

1. Age

2 Gender:

- a. Male () b. Female ()

3 Sexual Orientation.

- a. Heterosexual () b. Homosexual () c. Bisexual ()

4. Race.

- a. Asian ()
b. Afro- Carribean ()
c. Aboriginal/ Torres Strait Islander ()
d. Caucasian (White) ()
e African ()
f Maouri ()

5 What is your current marital status (ie to a woman) ?

- a Single () b. Currently married () c. Separated ()
d.Divorced () e. Widowed () f. In a "de facto"
relationship ()

6 Occupation.....

(Please just state this in general terms eg, Secondary School Teacher, Unemployed, Beneficiary, University Student, Retail Manager).

7 Usual place of residence.

- a. Metropolitan (ie Sydney) () b. Urban (ie Wollongong) ()
c. Rural () d. Other(please state).....

8 Do you currently live :

- a. Alone ()
b. with parents/ family ()
c. with husband/wife ()

- d. with your lover ()
- e in a shared property ()
- f. with friends ()

9 Who knows your HIV status ?

- a. No-one ()
- b. Lover only ()
- c. Parents only ()
- d. Family and Close friends ()
- e. All personal contacts ()

10 In order to travel to hospital appointments do you use

- | | |
|-------------------------|-----------------------------|
| a. Own car () | b. Public transport () |
| c. Volunteer driver () | d. Family / Friends car () |

11 How long on average does your journey take to hospital/clinic appointments?

- a. Less than 1 hour () b. 2 hours () c. 3 hours ()
- d. more than 4 hours () please state journey time.....

If you have any comments, suggestions to make about your healthcare and indeed generally about dealing with being HIV positive, please feel free to do so.

Thank you for your time and cooperation in completing this questionnaire.

Appendix 3 The interview schedule

The following were used only as a guide to the interviewer.

Introduction.

Reassurances re:confidentiality.

Permission to tape? Tape to be returned?

Key services provided: gaps and overlaps.

Constraints on the provision of services at present.

What are the areas of service deficit?

Which groups are currently not addressed by the service?

In an ideal world.....ideas, thoughts.

Barriers to service provision?

Do people with AIDS/HIV have unique needs?

What are the needs of people with HIV/AIDS?

Wind down interview. Thank participant.