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Evaluation of the National Centre for Gynaecological Cancers: final report

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Abstract

The Australian Government, under the auspice of Cancer Australia (CA), engaged the Centre for Health Service Development (CHSD) to conduct an independent evaluation of the National Centre for Gynaecological Cancers (NCGC). This final evaluation report synthesises our key findings and includes recommendations to position the work of the NCGC for the future. The evaluation has assessed the impact and outcomes of the NCGC at the level of consumers, service providers and the wider cancer control system. In addition we have reviewed the appropriateness, efficiency and effectiveness of the Centre in the context of government service delivery.

Keywords

centre, evaluation, final, national, report, gynaecological, cancers

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Cristina Thompson, Karen Quinsey, Elizabeth Cuthbert, James Dawber, Pamela Grootemaat, and Kathy Eagar



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Centre for Health Service Development

June 2010

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Abbreviations

ACCRM	Australian College of Rural and Remote Medicine
AIHW	Australian Institute of Health and Welfare
CA	Cancer Australia
CALD	Culturally and Linguistically Diverse
CDCP	Centers for Disease Control and Prevention
CHSD	Centre for Health Service Development
CIPHER	Centre for Innovation and Professional Health Education and Research
CEO	Chief Executive Officer
COSA	Clinical Oncological Society of Australia
CSIRO	Commonwealth Scientific and Research Organisation
CPD	Continuing Professional Development
DoHA	Department of Health and Ageing
FMA Act	Financial Management and Accountability Act
FTE	Full Time Equivalent
GCSDRF	Gynaecological Cancers Service Delivery and Resource Framework
MDA	Medical Defence Australia
NBOCC	National Breast and Ovarian Cancer Centre
NCGC	National Centre for Gynaecological Cancers
NHMRC	National Health and Medical Research Council
NICS	National Institute of Clinical Studies
NILS	National Institute of Labour Studies
OVCA	Ovarian Cancer Australia
PBS	Portfolio Budget Statements
PdCCRS	Priority-driven Collaborative Cancer Research Scheme
RACGP	Royal Australian College of General Practitioners
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCNA	Royal College of Nursing, Australia

Key Messages

The strengths of the National Centre for Gynaecological Cancers (NCGC)

- Overall, the NCGC is performing well. It is addressing its key objectives, fulfilling its role and implementing its activities effectively. Major successes include:
 - building and improving collaborations between organisations and stakeholders
 - engaging consumers and providing them with support, information and involvement
 - networking the clinicians and researchers in the gynaecological cancers area.
- The NCGC has a similar focus to comparative international approaches to gynaecological cancer management.
- The work of the Centre is informed by a National Advisory Group which adds considerable value.
- The NCGC has correctly identified its target audience and is aware of groups requiring greater input.
- There is a high level of personal satisfaction amongst those involved with the NCGC.
- Meaningful engagement has been a hallmark of the NCGC approach with consumers participating in all aspects of the Centre.
- The NCGC effectively establishes collaborative and active partnerships. The most critical partnerships are with professional associations and other jurisdictions.
- The NCGC has effectively engaged with a wide group of stakeholders. The high expectations of these stakeholders have generated a breadth of projects that align with the organisation's mandate.
- The highest level of investment is occurring in projects focused on building the capacity of the health workforce.
- The NCGC has efficient project management processes in place and has demonstrated effective monitoring of project delivery.
- Internally the NCGC has leveraged off the success of Cancer Australia (CA) initiatives such as CanNET and the Priority-driven Collaborative Cancer Research Scheme (PdCCRS).
- There is clear support and appreciation for the staff of the NCGC. Stakeholders consistently reported positive experiences with all staff.

Opportunities for further development

- The NCGC has not been operating long enough or been funded to the extent required to generate tangible and widespread health improvements at this stage.
- The corollary is that the NCGC has found it difficult to establish a national identity and a national leadership role.
- While the NCGC has efficient project management processes in place, many projects are not yet at the stage of implementation to generate project impacts
- There is a need for the work of the NCGC to continue. Gynaecological cancers continue to represent a significant disease burden for Australian women and there is evidence of significant health need.
- The key strategic issues for the NCGC are its sustainability and the availability and quantum of ongoing funding.

- While the NCGC has correctly identified its target audience, difficult to access, high risk groups require sustained investment in resources and effort.
- More work is needed to engage clinicians in the work of the Centre and develop workforce capacity. This is a pivotal relationship in terms of the sustainability of the NCGC.
- It is timely to review the Terms of Reference and membership of the National Advisory Group.
- The NCGC should adopt a small suite of key performance indicators (KPIs) that the Advisory Group routinely monitors over an extended period of time.
- The NCGC has more to do in terms of disseminating its outputs and increasing its profile nationally.
- The program logic developed as part of this evaluation provides a way forward. If the NCGC implements projects that address the 'required changes' described in the program logic, with appropriate and where possible evidence based strategies, then it is plausible that these interventions will lead to improved health outcomes for women with gynaecological cancers, their carers and families.
- There are divided views in the sector as to the sustainability of the NCGC as it currently exists. The recently announced merger between CA and the National Breast and Ovarian Cancer Centre (NBOCC) is generally seen as a positive step and it provides an important opportunity to better position the work of the NCGC into the future and integrate efforts to improve gynaecological cancer outcomes.

Executive Summary

The Australian Government, under the auspice of Cancer Australia (CA), engaged the Centre for Health Service Development (CHSD) to conduct an independent evaluation of the National Centre for Gynaecological Cancers (NCGC). This final evaluation report synthesises our key findings and includes recommendations to position the work of the NCGC for the future. The evaluation has assessed the impact and outcomes of the NCGC at the level of consumers, service providers and the wider cancer control system. In addition we have reviewed the appropriateness, efficiency and effectiveness of the Centre in the context of government service delivery.

The NCGC

Gynaecological cancers represent a significant disease burden for Australian women. The overarching goal of the NCGC is to improve outcomes for women with gynaecological cancers, their carers and families. It aims to achieve this through four key objectives:

1. Improve information and supportive care for women, their carers and families
2. Support the workforce to deliver coordinated quality gynaecological cancer care
3. Build the evidence base for control of gynaecological cancers, including through research and clinical trials
4. Build the collaborative partnerships to improve outcomes for people affected by gynaecological cancers.

The NCGC is a virtual centre based within CA. It has 2.1 Full Time Equivalent (FTE) staff and an annual budget of \$1.7M. It has been in operation for a little over three years. CA has recently merged with NBOCC and the organisation is currently in a transition phase.

The objectives and priority projects for the NCGC, documented in the Centre's Work Plan, are summarised in Appendix 1. This Work Plan extends across the funded budget cycle from 2008/2009 to 2010/2011. These priorities align with organisational objectives and the intent of the Senate Inquiry that produced the *Breaking the Silence* report.

The NCGC has a similar focus to comparative international approaches to gynaecological cancer management. The NCGC is working to improve gynaecological cancer outcomes for diverse groups of women, their carers and families. This includes reducing disparities within and between groups with the poorest health outcomes. The NCGC has struggled to engage some high-risk groups. This is not an issue unique to the NCGC as CA has similar responsibilities to reduce inequalities in cancer health outcomes for disadvantaged groups. Difficult-to-access and high-risk groups require a sustained investment in resources and effort.

Key evaluation findings

The NCGC is performing well. It is addressing its key objectives, fulfilling its role and implementing its activities effectively. Despite only being recently established, the general feedback strongly indicates that the perception of respondents is that the NCGC is bringing about a positive impact for women with gynaecological cancer, their carers and families. However, an unintended consequence of establishing the NCGC as a 'Centre' as opposed to a program is that this has raised huge expectations, particularly amongst service providers. Not all of those expectations have been met.

It is not possible to evaluate whether the NCGC has improved outcomes for women with gynaecological cancers, their carers and families at this stage. It has not been operating long enough or been funded to the extent required to generate tangible and widespread health improvements as yet. It is however, mostly doing the right things that will plausibly influence the

'required changes' that lead to improved outcomes. Generating improved outcomes will be the result of many different factors, interventions and contributors.

Engagement

Meaningful engagement has been a hallmark of the NCGC approach with consumers participating in all aspects of the Centre. Data consistently show that consumers working with the NCGC feel their contributions are welcomed and uninhibited by the NCGC. Consumers reported the recent *Development and Implementation of Resources for Consumers and Health Professionals* as a recent example of positive consumer engagement.

The size and scale of the NCGC has led to a deliberate strategy of collaboration and partnership development to achieve the objectives of the Centre. There is strong evidence that this approach has been successful. A major challenge for the NCGC is the ongoing engagement of a wide group of stakeholders. This varied mix of stakeholders has had a direct impact on the NCGC Work Plan, resulting in the broad approach taken to project selection. The NCGC delivers a diverse range of projects efficiently and effectively. Most projects have been completed on time and with the agreed outputs.

The Centre has been successful in working closely with all sectors and other stakeholders such as consumers and health professionals with its greatest achievements, its approach to consumer engagement and the establishment of active collaborative partnerships. It has delivered what it said it would, within acceptable timeframes and allocated resources. It has provided direct benefit to consumers associated with the NCGC and is poised to deliver genuine contributions to workforce capacity and the evidence base for control of gynaecological cancers.

The National Advisory Group has a critical role in advising on the priorities of the NCGC and overseeing project delivery. This Group also makes a key contribution to the strategic directions of the Centre. The National Advisory Group is a major stakeholder in this evaluation and has been engaged throughout this process.

Program and project management

The NCGC spends a large amount of effort in administering grants and overseeing project delivery and it does this well. Internally the NCGC has leveraged off the success of CA initiatives such as the CanNET project and Priority-driven Collaborative Cancer Research Scheme (PdCCRS). The NCGC uses the PdCCRS as a vehicle to administer their research activities. The NCGC is a funding partner in this scheme. No research outcomes have been generated yet. The development of clinical practice guidance materials for the management of women with endometrial cancers is in progress. Several stakeholders expressed concern at potential duplication, particularly in the area of clinical guideline development. The NCGC has had limited reach to date in terms of distributing service provider resources, however this is set to change in the next year as the outputs become available from the *Psycho-sexual Care Module etc.*

The NCGC has been effective in ensuring full utilisation of its budget in 2008/2009. It is currently on track to achieve this same outcome for 2009/2010. The highest level of investment is occurring in projects focused on building the capacity of the health workforce.

Capacity building and dissemination

The NCGC has built capacity in both consumers and service providers and its own personnel through their shared experiences in project working groups. The approach that the NCGC has taken to managing gynaecological cancers could potentially be a model for other cancers, through CA. The NCGC has acquired substantial methodological knowledge that is being fed back into CA. The NCGC has more to do in terms of disseminating its outputs and increasing its profile nationally. There has been a lack of resources for the promotion of the work of both the NCGC and CA.

The future

The NCGC is yet to establish a national identity and leadership role. Its strategy to date has been to target stakeholder as leaders with the role of the NCGC being to bring partnerships together and build leaders 'out there' (in the field as opposed to within the Centre).

To date there has been a level of disconnect between the inputs and activities of the Centre and the desired outcomes. While there is an established evidence base on the components and processes of care that are necessary to optimise gynaecological cancer outcomes (see discussion on program logic in Section 3.3), the priorities of the NCGC do not comprehensively reflect this evidence base. In part this is because other organisations are responsible for some components (eg, the NCGC is not responsible for screening). But it also reflects the fluid way in which the work program of the centre was originally determined. However, most of the missing elements have been identified in the newly developed *Gynaecological Cancers Service Delivery and Resource Framework* and it and the program logic in Section 3.3 provides a causal path that can be used in the future to determine work priorities. An ongoing challenge for the NCGC is ensuring appropriate monitoring and evaluation of its work that is consistent with the broader approach of CA.

There are divided views as to the sustainability of the NCGC as an organisation. Firstly, the NCGC should continue but it is time for the structure of the NCGC to be revisited. Secondly, there would be benefits of joining the ovarian cancer component of NBOCC with the NCGC component. Inter-jurisdictional partnerships and engagement with professional associations provide the best chance for sustainability of selected interventions.

In conclusion, whilst the evaluation has identified some areas for improvement for the NCGC, there are many positive and encouraging findings about the Centre and its activities. In our estimation the NCGC appears to be functioning effectively and progressing towards its future goals and will benefit from ongoing monitoring against an agreed suite of KPIs.

Summary of recommendations

The following recommendations are provided for the consideration of the CA Chief Executive Officer and NCGC Advisory Group:

1. The NCGC should position itself as a leading example of national cancer program management.
2. The Advisory Group should be retained with revised terms of reference and a review of membership to ensure all States and Territories participate.
3. The program logic set out in this report should be reviewed, amended as necessary and used as a compass to assess new project proposals and direct KPI development. The objectives of the NCGC remain appropriate and relevant.
4. The NCGC should develop a small suite of KPIs that are routinely reported to the Advisory Group. They will align with the requirements of DoHA and the priority areas where the Centre is aiming to have greatest impact.
5. Sustained efforts are required to address the needs of women with the poorest gynaecological health outcomes within the limits of available resources. These may be best implemented as part of a broader CA or Departmental strategy and include more emphasis on prevention and early detection.
6. The NCGC should explore alternative procurement models that comply with legislative guidelines but allow it to access appropriate clinical and technical expertise on an ongoing basis.

7. There should be wide engagement with key stakeholder groups over future priorities and the formulation of an annual NCGC Work Plan. The Work Plan should be endorsed by government and align with available resources. These discussions should be supported by considering the latest available evidence.
8. All future project proposals should include a monitoring and evaluation plan that is resolved at the project design stage. This will ensure appropriate data collection to monitor the implementation and impact of projects. Evaluation should be periodic and may not be appropriate for smaller, short-term projects.
9. The NCGC should move toward three year grant funding projects for all research initiatives to align with the majority of other PdCCRS grants. This may result in a wider range of applicants and lead to more 'co-funding' opportunities as most other funders provide resources for a three year period.
10. The NCGC should investigate the potential to link its existing NICS fellowships to its research grants. For example, the NICS fellowships could be tied to implementing research findings that come out of the PdCCRS – this would lead to a continuum of effort. This also recognises that there are different skills required to research as opposed to effectively translate research into policy and practice.
11. The NCGC should continue to build the skill base of NCGC personnel in the field enhancing their understanding of gynaecological cancer and its impact on people, the current evidence base and critical appraisal skills.
12. Investment should be maintained in the training and support of gynaecological cancer consumers, their carers and families.
13. The NCGC needs ongoing investment in establishing and maintaining consumer and professional networks in the field. It may be useful to develop some partnership instruments to formalise these relationships. For example, working collaboratively with Medical Colleges in developing programs that attract Government start up funding, that engage health care professionals and can be implemented across the entire country.
14. The NCGC needs to continue to work to bring relevant organisations under one umbrella – providing strong and credible national leadership in a model that unites consumer, clinical and bureaucratic voices.
15. Consideration should be given to the appointment of a high profile patron to improve the visibility of the Centre and the organisation's profile amongst Australian women. This should be part of a comprehensive marketing and communication strategy, that is appropriately resourced and aligned with CA.

1 Introduction

The Centre for Health Service Development (CHSD) is a research centre of the Sydney Business School, University of Wollongong. The Australian Government, under the auspice of Cancer Australia (CA), engaged the CHSD to conduct an independent evaluation of the National Centre for Gynaecological Cancers (NCGC). This evaluation commenced in August 2009.

This report synthesises our key findings from the evaluation and includes recommendations to position the work of the NCGC for the future. Our evaluation framework has assessed the impact and outcomes of the NCGC at the level of consumers, service providers and the wider cancer control system. In addition we have reviewed the appropriateness, efficiency and effectiveness of the Centre in the context of government service delivery. We have also posed key formative, summative and developmental evaluation questions. This report is structured to address these questions.

1.1 *Cancer Australia and the National Centre for Gynaecological Cancers*

CA is a statutory agency of the Department of Health and Ageing (DoHA), established under the *Cancer Australia Act 2006* to help reduce the impact of cancer in the community. It is a prescribed agency under the *Financial Management and Accountability Act 1997 (FMA Act 1997)* and is also subject to the *Public Service Act 1999* and the *Auditor-General Act 1997*. The Chief Executive receives direction from the Minister for Health and Ageing annually through the *Portfolio Budget Statements – Health and Ageing*, and the *Chief Executive's Instructions*. The *Cancer Australia Act 2006* lists several functions which direct the work of this agency.

In February 2007, the Australian Government provided funding of \$1 million to establish the NCGC as a virtual centre based within CA. At this time the NCGC was funded for one year only. In 2008, further funding of \$5.1 million over three years (\$1.7 million per annum to 30 June 2011) was allocated to the NCGC. The staff establishment of the NCGC has until recently consisted of approximately 2.1 Full Time Equivalent (FTE) personnel, including the National Manager NCGC/Consumer Support.

Gynaecological cancers are cancers of the female reproductive system, including the uterus (and endometrium), ovary, cervix, vulva, vagina and placenta and pregnancy-related cancers (referred to as gestational trophoblastic disease). As a group of cancers, gynaecological cancers are the fourth most common form of cancer for Australian women and the fifth most common form of cancer causing premature death in Australian women.¹

1.1.1 Governance

The NCGC operates under the auspice of CA and the Australian Government and its work is informed by a National Advisory Group of consumers, health professionals, researchers, health policy makers and representatives of cancer organisations. Members are invited because of their experience and expertise across the cancer continuum; they do not represent particular groups or organisations. Several working groups have been established, which are time limited and constituted to support specific projects of the NCGC. These groups include representatives of the over-arching Advisory Group and other members relevant to the specific project.

The NCGC National Advisory Group has a critical role in advising on the priorities of the NCGC and overseeing project delivery. This Group also makes a key contribution to the strategic directions of the Centre. The National Advisory Group is a major stakeholder in the evaluation and has been engaged throughout this process.

¹ Accessed 21 May 2009 at http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/gynaecological_cancer/index.htm

1.1.2 Priorities

The objectives and priority projects for the NCGC, documented in the Centre's Work Plan, are summarised in Appendix 1. This Work Plan extends across the funded budget cycle from 2008/2009 to 2010/2011 and arose in part from the Australian Government's response to the Senate Community Affairs Reference Committee Report on the Inquiry into Gynaecological Cancer in Australia. The committee published its report, *'Breaking the silence: a national voice for gynaecological cancers'*, in October 2006.²

The overarching goal of the NCGC is to improve outcomes for women affected by gynaecological cancers and their families and caregivers. It aims to provide national leadership to improve outcomes for women with gynaecological cancers and increase awareness and education among medical and allied health professionals.³ It does not provide direct cancer services or advice about cancer issues for individuals.

The Australian Government's *Portfolio Budget Statements for the Health and Ageing Portfolio 2009-2010* document the priorities for the NCGC relevant to this evaluation period and note:

*'The challenge for the Centre will be to gain improved outcomes across cancer control, including primary care and the private and public sectors. This will be achieved by working closely with these sectors and other stakeholders such as consumers and health professionals.'*⁴

The qualitative deliverable specified for the NCGC in the Australian Government's *Portfolio Budget Statements for the Health and Ageing Portfolio 2010-2011* is as follows:

'Manage and coordinate program activities that will improve information and resources, support the workforce and help build the evidence in gynaecological cancers.'

The 2010-2011 Reference Point or Target is listed as:

*'Program objectives achieved, for the coordination of the gynaecological cancer workforce initiative in collaboration with states and territories by June 2011.'*⁵

1.1.3 Organisational Context

This evaluation of the NCGC was initiated by CA in recognition that funding for the NCGC would lapse in June 2011 and an independent evaluation would assist the Centre in any future funding reviews. There was also a desire to improve the current approach and consistency of program evaluation within the NCGC and CA, to facilitate comparative analysis.⁶

Shortly after this evaluation commenced, DoHA initiated an internal review of the respective roles of the NCGC and National Breast and Ovarian Cancer Centre (NBOCC). This review aimed to identify any perceived duplication of effort or complementarities in gynaecological cancer activities and programs between both agencies. A report was expected in the third quarter of 2009; however the outcome of this review is not publicly available and has therefore not informed this evaluation.

In late May 2010, we met with key staff members of CA and the NCGC to review our preliminary findings and discuss potential recommendations. At this time the Acting Chief Executive Officer, Dr Joanne Ramadge, advised that some internal restructuring was occurring within CA which

² Parliament of Australia, Senate Standing Committee on Community Affairs (2006) *Breaking the Silence: A National Voice for Gynaecological Cancers*. Commonwealth of Australia, Canberra.

³ NCGC Web-site. Accessed 17 June 2010 at <http://www.canceraustralia.gov.au/ncgc/about-centre/ncgc-homepage>

⁴ Australian Government (2009) *Portfolio Budget Statements 2009-2010 – Budget Related Paper No. 1.10: Health and Ageing Portfolio*. Canberra.

⁵ Cancer Australia: Agency resources and planned performance as documented in Australian Government (2010) *Portfolio Budget Statements 2010-2011 – Budget Related Paper No. 1.11: Health and Ageing Portfolio*. Canberra.

⁶ RFT CA 04/0809 *Evaluation of the National Centre for Gynaecological Cancers and Possible Future Evaluations Undertaken by Cancer Australia to other Agencies within the Health Portfolio – issued by the Commonwealth Department of Health and Ageing*. May 2009.

would result in mainstreaming of primary functions across the organisation and the development of a matrix-like organisational structure. This would facilitate the sharing of expertise and reduce duplication within the organisation.

In practice, this meant the NCGC would no longer be responsible for managing certain projects in isolation but could more readily leverage off the specialist skills of other CA staff. For example, data analysis would now be coordinated for all cancers by the research and clinical trials team, while the staff of the NCGC would continue to have input in a collaborative way. Similarly, lessons learned by the NCGC personnel in clinical guideline development could be transferred to the lung program, as personnel working within both of these 'programs' would report to the Acting National Manager, Education and Service Development. These changes were seen as beneficial by the NCGC staff and they did not anticipate any impact on their work priorities.

On the 15 June 2010, the Minister for Health and Ageing, the Hon Nicola Roxon MP, issued a media release entitled '*One Single, United and Stronger National Cancer Agency*'.⁷ This announced a significant strategic and organisational shift with the creation of a single national cancer control agency through the amalgamation of CA and the NBOCC. The media release notes:

'The proposed joint agency will have a clear leadership mandate across all cancers, and capacity to better focus on Cancer Australia's responsibilities under the Cancer Australia Act 2006.'

A Working Group has been established, chaired by the Commonwealth Chief Medical Officer, to oversee and advise on the proposed transition. A four-week consultation period has also been announced to allow consultation with key stakeholders. Dr Helen Zorbas, the current Chief Executive Officer of NBOCC, has been appointed the Chief Executive Officer of Cancer Australia with immediate effect for a three-year period.

In summary:

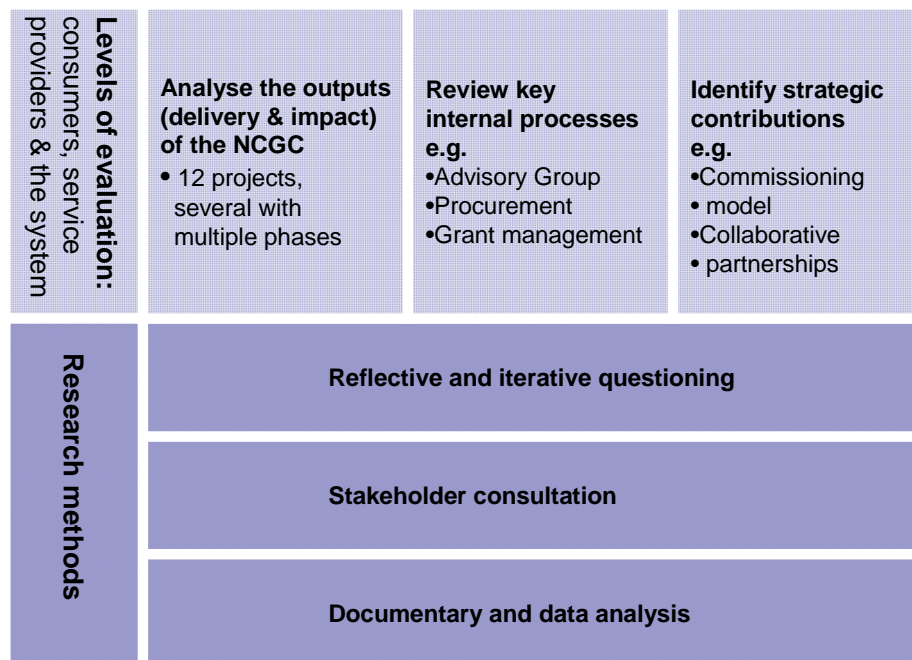
- The NCGC operates under the auspice of CA and the Australian Government.
- The work of the Centre is informed by a National Advisory Group.
- The NCGC is small with a limited staff profile and resource base. It has been in operation for a little over three years.
- The priorities of the Centre are documented in its three-year work plan which has been endorsed by the Australian Government.
- CA has recently merged with NBOCC and the organisation is currently in a transition phase.

⁷ Media Release '*One Single, United and Stronger National Cancer Agency*' issued by The Hon Nicola Roxon MP, Minister for Health and Ageing, 15 June 2010. Accessed 16 June 2010 at <http://www.canceraustralia.gov.au/media/files/ca/Media%20release%20Amalgamation.pdf>

2 Methodology

Our evaluation methodology is diagrammatically represented in Figure 1. Our evaluation findings are drawn from triangulating several data sources.

Figure 1 *NCGC evaluation design*



2.1 *Documentary and Data Analysis*

We have reviewed documentation relating to the multiple NCGC projects either completed or in progress. The minutes and papers of all Advisory Group meetings dating from the initial meeting in June 2007 to the present have also provided useful insights. A targeted review of academic and practice literature relating to international gynaecological cancer frameworks was completed. We analysed the *Senate Inquiry* recommendations in relation to the NCGC Work Plan. We have reviewed the content of the NCGC web-site and information relating to its maintenance.

2.2 *Stakeholder Consultation*

2.2.1 *Online Survey*

An online survey was issued to 61 stakeholders including clinicians, consumers, employees of CA, representatives of professional bodies and non-government cancer related organisations. Selected members of the NCGC Advisory Group, CA Advisory Council, CA Strategic Forum and various NCGC Working Groups were invited to take part. The aggregate output of this survey is included as Appendix 2.

In total, 49 of the 61 (80.3%) stakeholders who received the survey attempted to complete it. The data were checked for their quality, usability and consistency to ensure a robust analysis could be performed. Four of the 49 respondents did not consent to participate and five consented but answered few, or none, of the questions, leaving 40 (65.6%) complete and valid surveys which were used in the final analysis.

These 40 respondents included 11 (27.5%) who were involved in direct clinical service provision, leaving 29 (72.5%) who were not, (although this does not equate with non involvement in relevant cancer control areas). Twenty-three respondents indicated that they would be willing to participate in a semi-structured telephone interview.

2.2.2 Semi-structured Qualitative Interviews

A series of 25 extended qualitative interviews were conducted with a diverse sample of stakeholders, generating over 1100 minutes of recorded transcripts which were coded using the NVivo application. On occasion, direct quotes are used in this evaluation report. In keeping with best practice in qualitative analysis, a single quote is used purely to illustrate a consistent theme identified across several interviews.

Adequate representation was achieved across most key stakeholder groups, with the exception of DoHA and the NBOCC. Lack of participation by these groups represents a limitation to the interview findings. The announcement referred to in Section 1.1.3 took place subsequently and may have been a factor in the inability to engage these groups.

2.3 Reflective and Iterative Questioning

Representatives of the NCGC and CHSD established a small working group to manage the project, and met fortnightly by teleconference. A full day meeting was held at the beginning of the project to clarify the requirements of the evaluation, establish background and organisational context and agree on project management processes. In May 2010, a further one-day meeting occurred with representatives of the NCGC and CA. At this time we reviewed progress to date, clarified the audience for the final report and preferred format, explored preliminary findings and recommendations. This process provided opportunity for reflective and iterative questioning of emerging themes and findings.

2.4 Evaluation Design

The evaluation has several dimensions. We have investigated the impact of the NCGC at the level of consumers and carers, service providers (professionals, volunteers, organisations) and the broader cancer control system (structures and processes, networks, relationships). We have assessed the appropriateness, efficiency and effectiveness of the NCGC through a variety of methods; analysed the outputs of the NCGC; reviewed major internal processes; and identified key strategic issues and contributions for the NCGC.

Our evaluation framework was designed around six key questions (refer to Table 1), which, in keeping with the request for a 'plain language' style, will be used to structure this report.

Table 1 *Evaluation questions*

Key evaluation issues for the NCGC	
<i>'Plain language' questions</i>	<i>Corresponding evaluation issues</i>
What did you do?	DELIVERY
How did it go?	IMPACT
Can you keep it going?	SUSTAINABILITY
What has been learned?	CAPACITY BUILDING
Are your lessons useful for someone else?	GENERALISABILITY
Who did you tell?	DISSEMINATION

2.4.1 Attribution versus Contribution

In evaluating the NCGC and its projects, an important issue revolves around the idea of 'attribution'. In this context, attribution can be considered as an effort to measure 'causality' or the extent to which outcomes are the result of particular activities.

The Centers for Disease Control and Prevention (CDCP)⁸ note that determining attribution can be unrealistic in community based public health programs because multiple service providers and funders are often addressing similar objectives. As a result, widely used indicators for tracking health outcomes (such as improved survival rates for ovarian cancer) are affected by many factors and cannot be attributed to the impact of a particular program.

The CDCP suggest that a more realistic approach to measuring program effectiveness is to measure the extent to which a program has made a 'contribution' towards achieving long-term goals. Here, the aim of the assessment is to make an informed and evidence-based judgement about the overall contribution of a program or project to a long-term objective.

In this context, the aim becomes to ensure that the evaluation framework, the performance indicators and the related data collection provide a sufficient picture of the achievements of a project to make an informed judgement. If data are collected in accordance with an agreed data protocol, and the subsequent data analysis indicate that a project has met its performance indicators, it becomes reasonable to conclude that the project has made a 'contribution' to achieving the program's overall aims and objectives.

In our view, the NCGC clearly fits within a model where it is reasonable to aim to measure 'contribution' rather than 'attribution' and this approach has underpinned the evaluation. The NCGC does not work in isolation and is only one of many players in the cancer control sector. It alone cannot improve health outcomes for women with gynaecological cancers, their carers and families. It would be an interesting exercise to map the whole of government effort at national and state levels in cancer control, across the required changes specified in the program logic. This is, however, outside the scope of this evaluation.

In summary:

- Evaluation findings are drawn from triangulating several data sources.
- This evaluation has several dimensions including:
 - the impact of the NCGC at the level of consumers and carers, service providers and the broader cancer control system
 - the appropriateness, efficiency and effectiveness of the NCGC
 - analysis of the outputs, internal process and strategic contributions of the NCGC.
- The NCGC fits within a model where it is reasonable to aim to measure 'contribution' rather than 'attribution' and this approach has underpinned the evaluation.

⁸ The Centers for Disease Control and Prevention (1999). *Framework for Program Evaluation in Public Health*. MMWR 48 (RR11): 1-40.

3 Findings

It is not the role of this evaluation to assess individual projects but rather to assess the overall contribution of the NCGC through the sum of its initiatives. The various sources of data and information have been synthesised and analysed to produce our findings.

3.1 Target Groups for the NCGC

The NCGC is working to improve gynaecological cancer outcomes for diverse groups of women, their carers and families. This includes reducing disparities within and between groups with the poorest health outcomes, particularly:

- Aboriginal and Torres Strait Islander women
- Culturally and Linguistically Diverse (CALD) women
- Women living in rural and remote locations

The other primary target group for the NCGC is clinicians and service providers working in:

- Primary care
- Generalist health care
- Specialist health care.

The NCGC has struggled to engage some high-risk groups. At this stage only small, time-limited projects have been funded. For example, under the *Building Cancer Support Networks* initiative a cancer support group for Aboriginal and Torres Strait Islander women was funded in Geraldton, WA. The *Psycho-sexual Care Module* under development includes case studies specific to women who are culturally and linguistically diverse. Through the *Development and Implementation of Resources for Consumers and Health Professionals* there was general recognition that it is useful to produce consumer information in various languages; however this was not within the scope of the project. Whilst developing multi-lingual and culturally appropriate resources is costly and requires expertise, many stakeholders saw it as the first step in engaging CALD communities.

This is not an issue unique to the NCGC as CA has similar responsibilities to reduce inequalities in cancer health outcomes for disadvantaged groups. Other agencies consistently commented on the challenges in appropriately engaging these groups. Difficult-to-access and high-risk groups require a sustained investment in resources and effort. There appears to be limited value in persisting with short one-off projects. There is a need to enter into genuine strategic partnerships with these groups using a holistic approach, for example, through the Aboriginal Medical Services throughout States and Territories or the National Aboriginal Community Controlled Health Organisations (NACCHO) and the Federation of Ethnic Communities Councils of Australia (FECCA) infrastructure. Time-limited projects make it impossible to engage appropriately unless the NCGC has established networks. Work with disadvantaged women needs to be part of a broader community participation strategy for the Centre and CA.

The current project between CA and Cancer Voices in South Australia called '*Cancer Conversations*' was recommended as a potential option for the future. Cancer conversations are facilitated or mediated telephone conversations with indigenous people which allow them to find out information without leaving home. They remain on their land and retain the support of their clan or elders through this conversational process. It is still early in its implementation and the evaluation results should be closely reviewed by the NCGC as this approach may offer a novel way of engaging indigenous Australians.

3.2 Stakeholder Engagement

A major challenge for the NCGC is the ongoing engagement of a wide group of stakeholders. This varied mix of stakeholders has had direct impact on the NCGC Work Plan, resulting in the broad approach taken to project selection. The NCGC needed to engage as many stakeholders as possible early in its life cycle. It has tried to do this through inviting participation in the Advisory Group and/or through membership of project working parties. This has required a range of projects that not only aligned with the mandate of the NCGC and Cancer Australia but captured stakeholder interest.

Two contrasting views of this approach emerged during the evaluation. The dominant view was that this diverse range of disparate projects was overly ambitious and generated pressures for the Advisory Group and the NCGC workforce. It necessitated a reliance on external providers because of the varied skills and expertise required across the suite of projects and therefore focused the NCGC on grant and/or project management. However, a positive consequence of this diversity was the importance of partnerships or collaboration to achieve the work of the NCGC. An example of this is illustrated through the use of the *National Institute of Clinical Studies* to manage the *Clinical Research Fellowships* and the efforts to work with the *Winston Churchill Memorial Trust* to establish the *Consumer Fellowships* (noting that the success of this strategy varied).

The opposing view was that this range of projects had been necessary from the inception of the NCGC because of the high expectations of diverse stakeholder groups and pressure to produce early results. The range of projects was also necessary to address all organisational objectives. It was understood that contributions to the evidence base and workforce capacity would take time and that many of the earlier projects would provide building blocks for subsequent work. Examples of this include the *Review of the Gynaecological Workforce* which is now informing the *Development of the Gynaecological Cancers Service Delivery and Resource Framework* and related *Jurisdictional Projects (Development and Implementation of the Gynaecological Cancers Service Delivery and Resource Framework)*.

This theme is illustrated by the following quote:

'...I think that they have to attempt to address a diverse range of interests. I do. I just don't think that they would survive if they didn't. But I do think, yes, some clarity around priorities and articulating that to the community is critical...the attempt to be everything to everyone is just never going to work, but the whole communication around how you set priorities and how it's got to be, if that's going to work, it's got to be pretty good.' (Stakeholder Interview, 2010).

The major stakeholder groups of the NCGC are listed below:

- Consumers – women with gynaecological cancers, their carers and families
- Clinicians and service providers
- Professional associations
- Consumer organisations
- General community
- Government – Various Commonwealth agencies and departments, particularly DoHA; State and Territory jurisdictions and NBOCC
- Cancer related agencies e.g. The Cancer Council
- NCGC and CA employees
- NCGC Advisory Group; CA Advisory Council and CA Strategic Forum members
- Universities

3.3 NCGC Program Logic

Our evaluation design has included the drafting of a simple program logic for the NCGC. Program logic is a way of developing a program plan using pictorial representations of what you want to achieve linked to what is required to achieve them. The logic model was characterised initially by program evaluators as a tool for identifying performance measures and since that time has been adapted for program planning.⁹

Another more recent definition used by the Prevention Research Centers at the US Center for Disease Control and Prevention stated that:

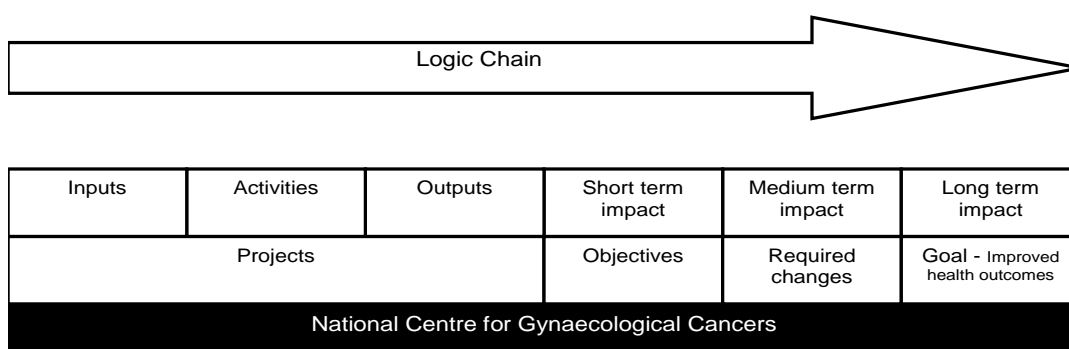
‘A logic model visually links program inputs and activities with program outputs and outcomes and shows the basis (logic) for these expectations. The logic model is an iterative tool, providing a framework for program planning, implementation and evaluation.’¹⁰

The basic premise of program logic is to make explicit the logic chain that links projects to objectives and the goal of the organisation. The aim is to ‘test’ whether the activities of the NCGC will ultimately lead to the achievement of ‘improved health outcomes for women affected by gynaecological cancers and their families and carers’.

The evidence base for cancer care provides impetus for ‘required changes’ in service delivery. The consultation process aimed to test stakeholder views on these ‘required changes’, specifically the components and processes of care which, according to the evidence, directly affect the health outcomes of women with gynaecological cancers.

In the language of program theory, the projects of the NCGC, staff, financial resources and Advisory Group represent the ‘inputs, activities and outputs’ of the logic chain. The objectives of the NCGC specify what needs to be achieved in the short term; the required changes specify what this leads to in the medium to longer term, which is the achievement of the organisational goal (refer to Figure 2).

Figure 2 Constructing a logic chain



The logic chain should include the ‘required changes’ to achieve the NCGC’s overarching goal. A goal provides an aspirational target that is long term – it implies movement from a current state to a future state. For this ‘movement’ to occur, an organisation must understand what actions are most likely to lead to change. However, these actions are not explicit in the NCGC Work Plan.

The overarching goal of the NCGC is stated on the organisation’s web-site:

⁹ McCawley P.F. (1997) *The Logic Model for Program Planning and Evaluation*, CIS 1097 (Moscow, Idaho: University of Idaho Extension Program). Accessed 18 Feb 2010, <http://uidaho.edu/extension/LogicModel.pdf>

¹⁰ Sundra DL, Scherer J and Anderson LA (2003). *A guide on logic model development for CDC’s prevention research centres*. Prevention Research Centers Program Office. Centers for Disease Control and Prevention.

*'The National Centre for Gynaecological Cancers is an Australian Government initiative to improve outcomes for women affected by gynaecological cancers and their families and caregivers.'*¹¹

This goal is supported by the multiple projects that are listed in the NCGC Work Plan.¹² Each project is linked to one of the organisation's four key objectives:

- Objective 1:** Improve information and supportive care for women with gynaecological cancers, their carers and families
- Objective 2:** Support the workforce to deliver coordinated quality gynaecological care
- Objective 3:** Build the evidence base for control of gynaecological cancers, including through research and clinical trials
- Objective 4:** Build collaborative partnerships to improve outcomes for people affected by gynaecological cancers.

Based on these objectives, our knowledge of the evidence and consultation with the NCGC staff, the following set of 'required changes' was identified for inclusion in our program logic model.

Women need access to:

- screening
- early diagnosis
- best practice treatment and care (this includes multidisciplinary management and support during treatment as per the NCGC Gynaecological Cancers Service Delivery and Resource Framework)
- supportive care (good supportive care is assumed to refer to the period during treatment and beyond and include follow up; post treatment surveillance, survivorship and palliative care).

Care needs to be:

- coordinated
- multidisciplinary and integrated
- accessible and of quality (high quality and as close as possible to home).

Women, their families and caregivers require help to make the best decisions through:

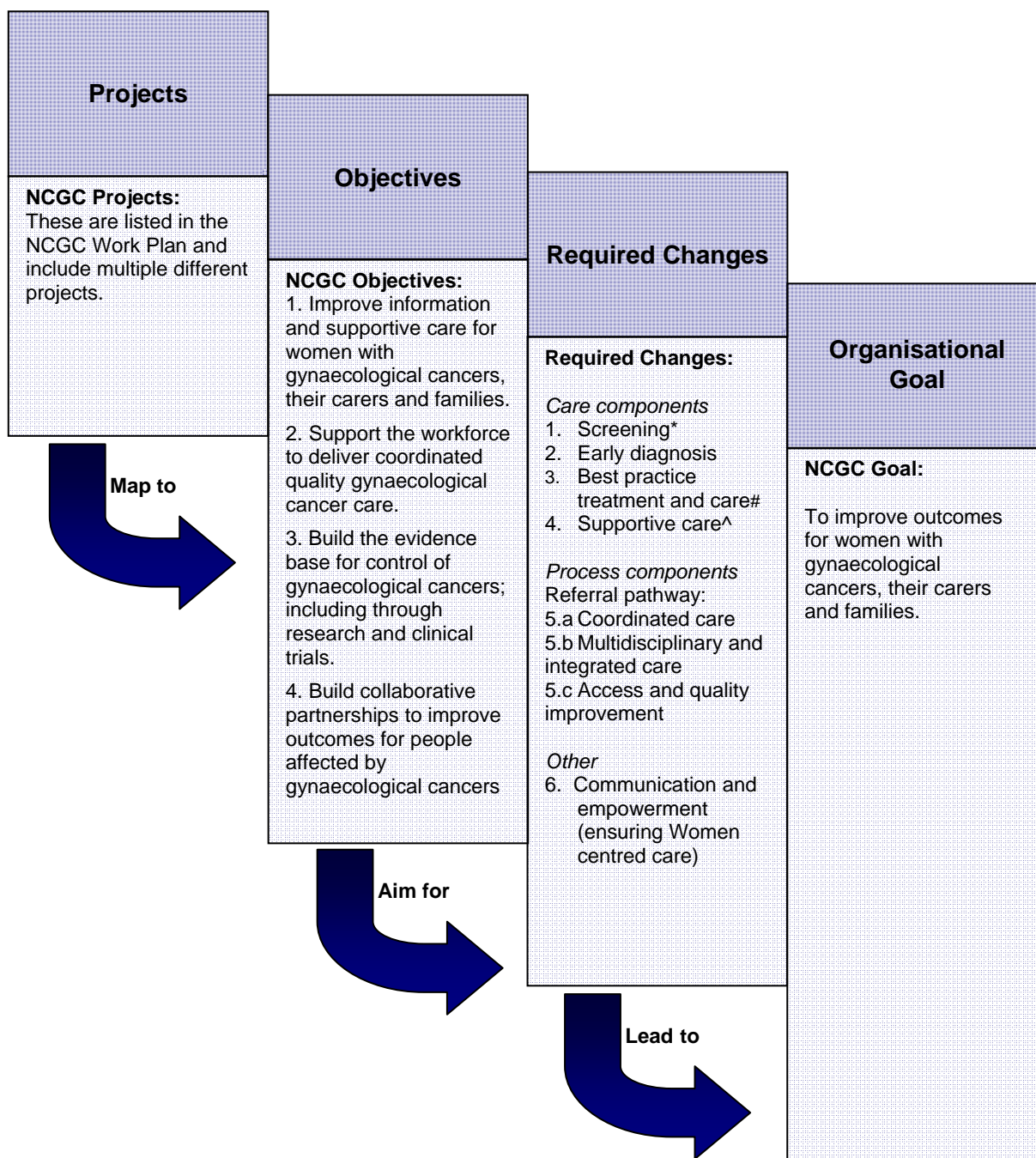
- communication and empowerment (ensuring Women centred care).

Our representation of the NCGC's program logic is provided in Figure 3. This was reviewed against the recently circulated National Gynaecological Cancers Service Delivery and Resource Framework (NGCSDRF) that is being developed as part of the NCGC's major workforce initiative. It incorporates the same stages of care outlined in that document.

¹¹ Accessed 29 March 2010 at: <http://www.canceraustralia.gov.au/nccg/about-centre/nccg-homepage>

¹² NCGC Work Plan 2010 (Internal correspondence from the NCGC to CHSD)

Figure 3 NCGC program logic



* The NCGC does not have responsibility for screening for gynaecological cancers; this is managed by the Department of Health and Ageing.

Best practice treatment and care includes multidisciplinary management and support during treatment as per the *National Gynaecological Cancers Service Delivery and Resource Framework*.

^ Supportive care is assumed to refer to the period during treatment and beyond and include follow up; post treatment surveillance, survivorship and palliative care.

The relationship between NCGC projects, objectives and the required changes leading to the long-term health outcome goal, are summarised in a matrix in Table 2.

Table 2 *Project matrix*

Projects	Objectives	Goal: To improve outcomes for women with gynaecological cancers, their carers and families
		Required Changes
5; 6a; 6b; 7a; 10	2 and 3	1. Screening*
6a; 6b; 8b; 9; 10	2 and 3	2. Early diagnosis#
5; 6a; 6b; 7a; 9; 10	2 and 3	3. Best practice treatment and care (treatment – including multidisciplinary management and support during treatment)
3; 4; 5; 6a; 6b; 7a; 7b	1, 2 and 3	4. Supportive care (including follow up; post treatment surveillance; survivorship and palliative care)
6a; 6b; 7b; 8a; 8b; 9		5. Referral pathway
6c; 6d; 7b	2 and 3	5a. Referral pathway – Co-ordinated care
6c; 6d; 7b	2	5b. Referral pathway – Multidisciplinary and integrated care
6d; 7b	2	5c. Referral pathway – Access and quality improvement
1; 2; 4	1	6. Communication and empowerment (Women centred care)
		System Enablers (including data development and strengthening the evidence base)
7b; 9; 11a; 11b; 12		

* All of these projects have potential to contribute to early screening however this is not their focus. The NCGC does not have responsibility for screening for gynaecological cancers; this is managed by the Department of Health and Ageing.

Some of these projects have not yet realised their potential to contribute to the required changes.

It should be recognised that the overarching goal of improved health outcomes for women with gynaecological cancer, their carers and families, is bigger than the NCGC. The NCGC came into existence relatively recently (in 2007) and occupies a fairly specialised niche within the spectrum of established cancer control organisations. Whilst screening is part of the ‘required changes’; this is not a role for the NCGC, as this function is provided by other agencies and divisions within DoHA. Although some NCGC projects may refer (and contribute) to screening, it is not the primary focus of these projects.

In summary

- The NCGC has correctly identified its target audience and is aware of groups requiring greater input.
- Difficult to access, high risk groups require sustained investment in resources and effort.
- The NCGC has effectively engaged with a wide group of stakeholders, the challenge will be maintaining this engagement.
- The high expectations of diverse stakeholders have required a range of projects that not only aligned with the mandate of the NCGC and CA and addressed all organisational objectives, but captured stakeholder interest.
- It was understood that contributions to the evidence base and workforce capacity would take time and that many of the earlier projects would provide building blocks for subsequent work.

4 Key Evaluation Questions

Findings about the outputs and impact of the NCGC have been summarised under the six key evaluation questions. They are drawn from the multiple sources of data gathered during the course of this evaluation.

4.1 What Did You Do?

The first step in this evaluation has been to assess the delivery of NCGC activities, focusing specifically on two questions:

- Has the NCGC done what it was intended to do?
- Is the NCGC doing the right things?

The NCGC has a Ministerial endorsed Work Plan that identifies priority projects across the three-year budget cycle. These projects have been clustered under their relevant objectives (see Section 4.2.3). When the NCGC was first established in 2007 several projects were transferred from other parts of DoHA. With the allocation of a further three-year funding, the NCGC continued existing projects and was able to establish new initiatives that aligned with their role and responsibilities. The Work Plan is project specific and not objective specific. Ongoing funding for the NCGC remains a key strategic issue.

4.1.1 Project Delivery

The NCGC has implemented and continues to implement the diverse range of projects included in its Work Plan. Many projects specified in the Work Plan are in progress, with the majority well advanced and on target for completion by 30 June 2011. Others have been completed: for example, the *'Development and Implementation of Resources for Consumers and Health Professionals'* delivered in collaboration with Dr. Norman Swan from GSB Consulting and the *'Development and Implementation of a Professional Development Package in Gynaecological Cancers for General Practitioners'* in conjunction with the Royal Australian College of General Practitioners (RACGP).

These projects involve a wide range of stakeholders and address differing target groups. They are all consistent with organisational objectives and have been endorsed by the Advisory Group. The NCGC has efficient project management processes in place and has demonstrated effective monitoring of project timeframes and outputs. There is effective inclusion of consumers in the project selection process and ongoing project management. Whilst a standard approach to project management is used, the NCGC personnel are flexible when necessary. Project participants found the start-up meeting particularly useful. This clarified expectations and developed a shared understanding of project requirements. It also facilitated agreement on the Project Plan. The clear communication channels established through fortnightly teleconferences, helped projects to stay on track. All projects are monitored closely for compliance with the contract. Most projects establish working groups which are mostly seen to be useful sources of technical advice. The Advisory Group provides an important role in project oversight and this is perceived as valuable due to the high level of clinical content in many projects. Evidence of how the NCGC has involved organisations is available from project working group records.

Projects are generally finished on time with definable outputs. There have been some problems with the quality and usefulness of outputs in certain projects and a perception that they did not necessarily come up with what people were looking for. This can partly be attributed to limitations in the experience and skills of the personnel contracted to deliver the project and inadequate critical appraisal of interim project outputs.

In all instances, the NCGC has been able to make the hard decisions necessary to get the project back on track, harness the requisite specialist expertise to improve the outputs or end the

contractual arrangement if issues could not be satisfactorily addressed. The amount of input required by the NCGC depends on the complexity of each project and other contextual factors. For example, at the commencement of the *Jurisdictional Projects (Development and Implementation of the National Gynaecological Cancers Service Delivery and Resource Framework)*, all States imposed a freeze on employment. This could not have been anticipated and resulted in project delays and renegotiation of project timeframes.

There is some frustration at the bureaucratic constraints that impact on project selection and management. This leads to some individuals feeling that their contribution is at times overlooked. A common criticism was the extended time it takes for projects to get up and running. The reasons for these delays were generally understood and they were most often attributed to government processes, e.g. procurement regulations. There is an ongoing need to ensure stakeholders working with the NCGC understand the constraints under which it operates and that many of the administrative processes to which it must adhere are derived from legislation (e.g. CA is an agency that must operate in accordance with the *Financial Management and Accountability Act 2007*).

Comments reflecting these issues are as follows:

'The bureaucracy around the Projects and Working Groups is cumbersome, though I recognise that this is 'imposed' from above and hard to reduce. It does seem to add inordinate time/costs to everything...' (Stakeholder Interview, 2010)

'... All projects are decided upon and we are then left to rubber stamp them.' (Stakeholder Interview, 2010)

'It seems to me that the NCGC 'bureaucracy' has at some times interfered with the direction that projects might take, possibly on a 'cost saving' approach.' (Stakeholder Interview, 2010)

The largest investment in project delivery is in *Supporting the Gynaecological Cancers Workforce*. This project has several phases which are designed to address various challenges relating to the provision of gynaecological cancer services by specialist and generalist health professionals and to provide a best practice framework and identify the gaps in meeting this framework within the current workforce. It aims to generate national agreement on best practice and models of care. It also identifies the challenges and constraints around how services are currently organised and highlights potentially useful ways forward. It is a key interim step to improving outcomes for women with gynaecological cancers through ensuring consistency in care.

In projects where specific technical or clinical expertise is required, there is a reliance on Advisory Group input. The plethora of working groups is quite burdensome for Advisory Group members and whilst many members contribute willingly and report satisfaction with their involvement, the quality of this input may be improved by reducing the number of groups.

Should the NCGC be funded from 2011/2012, it would be timely to review the breadth of project activity and concentrate on fewer priorities with the capacity to generate greater impact. Greater emphasis on inter-jurisdictional engagement particularly to develop workforce capacity and ongoing efforts to build the evidence base for the management of gynaecological cancers aligns best with the 'required changes' leading to improved health outcomes.

4.1.2 Monitoring and Evaluation

At the beginning of this evaluation the CHSD team established that we would not evaluate the impact of each project, as this was outside the scope of our engagement and problematic because of the varying stages of project implementation. We have, however, assessed the delivery of each project from the available documentation and through discussions with selected project leads and

NCGC personnel as a way of determining that the NCGC has or is continuing to do, what it was set up to do.

An ongoing challenge for the NCGC is ensuring appropriate monitoring and evaluation of its work that is consistent with the broader approach of Cancer Australia. Monitoring and evaluation generally support the three main functions of:

- accountability to funding bodies and key stakeholders
- project management and
- facilitation of learning to achieve results.¹³

This distinction between monitoring and evaluation is critical. Monitoring as defined by Markiewicz,¹⁴ is:

'the ongoing collection and analysis of information to both monitor the progress of implementation and determine whether results are being achieved...Monitoring is the continuous and systematic collection and analysis of information (data) in relation to a program or project that is able to provide management and key stakeholders with an indication as to the extent of progress against stated goals and objectives'

For some projects managed by the NCGC, the focus has been on monitoring processes such as the activities and outputs of projects. It may be useful when establishing contracts to require that projects in collaboration with the NCGC, establish a monitoring plan and monitoring activities. This would provide the NCGC clear information on what monitoring will be occurring and what data is being collected.

Evaluation as defined by Markiewicz¹⁵, is:

'the collection and analysis of information to determine answers to formative and summative evaluation questions in order to understand whether and how a program is meeting its stated objectives...Evaluation is the planned and periodic assessment of program or project results in key areas (e.g. appropriateness, effectiveness, efficiency, impact and sustainability).

The evaluation customarily builds on the monitoring process and identifies:

- the level of impacts and outcomes achieved
- the intended and unintended effects of these achievements
- approaches that worked well and those that did not work as well
- the reasons for success or failure and learning from both.

The evaluation process can also provide a level of judgment as to the overall value of the program or project.¹⁶

The NCGC should adopt a monitoring and evaluation framework as part of its routine project management processes. This could be achieved through use of a simple checklist to establish which projects require monitoring and/or evaluating. This could be reviewed during the development stages of each new project to determine the most useful way of assessing project delivery and impact. Common principles and/or guidelines are likely to be more useful for the NCGC as they could be applied to every commissioned project.

Appropriate monitoring needs to be built into every project to provide evidence of delivery and implementation and identify and address any data limitations relating to impact evaluation. If project evaluation is required, then an evaluation plan which details evaluation questions, evaluation activities and data collection sources could be part of the initial project set up

¹³ Markiewicz, A. (2010) *Monitoring and Evaluation Core Concepts* (Unpublished Seminar Paper)

¹⁴ Ibid, pp.2-5

¹⁵ Ibid, pp.2-7.

¹⁶ Ibid.

procedures. This would require a level of resourcing to enable this process to occur. It also may benefit from an Evaluation Reference Group or alternatively using the working parties established for key NCGC projects to support the project team and the NCGC in the design and implementation of monitoring and/or evaluation plans.

The diversity of NCGC projects makes it virtually impossible to design a meaningful evaluation tool that can be applied to each initiative. We came to this conclusion after completing a detailed evaluability assessment of each NCGC project.

4.1.3 Advisory Group

The Advisory Group has a key role in overseeing the work of the NCGC as described in its *Terms of Reference*. The membership of the Advisory Group has been relatively stable since its inception in 2007 with appointment of additional members occurring in 2009. On average, two meetings per year are held, one face-to-face and the other by teleconference. The Advisory Group has an independent Chair.

There is a good mix of expertise within the Advisory Group with members coming from diverse backgrounds and various States and Territories. Several members of the Advisory Group are also involved in other committees of Cancer Australia, professional associations and related cancer organisations. There is an appropriate balance between clinicians, professionals and consumers. There appears to be a relatively high level of agreement that participants can contribute effectively to the Advisory Group and a corresponding level of satisfaction in terms of members' involvement with the NCGC. There is a consistent view that the Advisory Group has an essential role and should remain involved in project selection and oversight. Advisory Group members were found to make positive contributions to project development when issues were presented to them for feedback.

There was, however, comment on the potential for wide differences of opinion on both the Advisory Group and Working Groups, about issues affecting service providers that have developed from the different ways that people think and practise. These differences appear to be acknowledged by most participants. There is a similar issue in respecting the experiences of consumers but at the same time reflecting diversity in experience.

Attendance at Advisory Group meetings is variable with consistently less than two-thirds of invited members attending. Over the past two years, the focus of the meeting has predominantly been on project delivery with comparatively less time spent on strategic issues. The meeting records show the Advisory Group's involvement in priority setting in mid 2007 and the establishment of the NCGC Work Plan. Whilst there has been some ongoing discussion of priorities, there does not appear to have been any major focus on this. It should be noted that the NCGC is working to a three-year budget cycle and the current Work Plan and priorities remain in train until June 2011. The NCGC has not received any additional funding for new project proposals over this period.

Given the recent developments within CA it would be timely for the Advisory Group to review its Terms of Reference. It may also benefit from some rejuvenation of its membership, particularly important is the recent inclusion of a clinical leader from Queensland. The role should continue to include the provision of advice on strategic directions, targeted input into project selection, implementation and evaluation and oversight and accountability for the NCGC generally. However, it may be useful to shift the attention of the Advisory Group to more strategic issues with less input into routine project work. Advisory Group members should receive ongoing education and information about how the 'machinery of government' works.

The role of the CA Strategic Forum and its link with the Advisory Group was seen as important. This is because the Strategic Forum includes State decision-makers and provides the opportunity for CA to engage with these stakeholders. This is critical for successful implementation of inter-jurisdictional initiatives, particularly the NCGC efforts in workforce development. The Advisory

Group would benefit from an improved feedback loop within CA, ensuring that they remain aware of the work of the CA Advisory Council and Strategic Forum.

4.1.4 Partnerships and Collaboration

The size and scale of the NCGC has led to a deliberate strategy of collaboration and partnership development to achieve the objectives of the Centre. It is seen by many stakeholders *'to be part of their DNA'*. Some partnerships have been general in nature without any specific purpose other than ongoing information exchange. However the majority have started from a particular need for skills or expertise, often arising from a project, for example, the *Development of the Minimum Data Set* for ovarian, cervical and endometrial cancers, in conjunction with the NBOCC.

There is consistent view that the NCGC effectively establishes collaborative partnerships and evidence that these are 'active' partnerships. The most critical partnerships are with professional associations such as RANZCOG, RACGP, Royal College of Nursing Australia (RCNA) and Australian College of Rural and Remote Medicine (ACRRM); and with other government agencies such as NBOCC and consumer organisations like Ovarian Cancer Australia (OVCA), The Cancer Council and Cancer Voices to name a few.

'...so I would say that in all of the sort of the communications that we've had the importance of engaging stakeholders, agencies, colleges the who's who in the zoo, really, has been a very clear focus of the Gynae Centre, ensuring that people are kept informed, that people are provided an opportunity to consult and participate and those sorts of things.' (Stakeholder Interview, 2010).

The NCGC recognises the importance of inter-jurisdictional partnerships. The continuing work of CanNET provides a conduit for the NCGC. The potential for either CA or the NCGC to establish a resource person in each state should be considered, if funding permits. CA could make each senior executive responsible for the primary liaison role with a couple of States and Territories to ensure continuity and coordinated approaches across all CA programs within States. A challenge with interjurisdictional engagement is the constant turnover of staff in States. The proposed national health reforms may result in further changes within State Health Departments.

'Just thinking from our own point of view when you get 30 people around a table it's a bit like a Tower of Babel but if there's central point that's important coming out of it they will want to be a part of it.' (Stakeholder Interview, 2010)

4.1.5 Consumer Engagement

The NCGC has adopted the CA approach to consumer engagement. CA has effective processes to recruit, train and harness a purposeful contribution from consumers. This received a further boost when the National Director of Consumer Engagement accepted responsibility for the NCGC from mid 2008 to June 2010.

Meaningful engagement has been a hallmark of the NCGC approach with consumers participating in all aspects of the Centre. Data consistently shows that consumers working with the NCGC feel their contributions are welcomed and uninhibited by the NCGC. There is very strong belief amongst key stakeholders that consumers benefit from the activities of the NCGC and positive results in relation to the perception of the way the NCGC treats consumers. There is a consistent view that the NCGC has seen this as very important and that it was 'high on their agenda' to enlist consumer and clinical support and they have done this effectively. They are seen to go out of their way to engage consumers in all facets of their work.

'It's a bit of a Vox Pop of what they're doing and how we feel it would be received and how appropriate it is and so they do seek our advice.' (Stakeholder Interview, 2010)

4.1.6 Leveraging from Cancer Australia

Internally the NCGC has leveraged off the success of the CanNET project implemented by CA as the CA approach is not program specific but applicable across tumour types. Many of the lessons learned in CanNET, particularly in terms of interjurisdictional co-operation, continue to inform the *Supporting the Gynaecological Cancers Workforce Jurisdictional Projects*. The NCGC is taking this further with several contracts in place for the *Workforce Projects* that are cross-jurisdictional. It is building on the work of CanNET in network development and implementation processes demonstrating they can be applied to gynaecological cancer management.

There have also been lessons learned from the CA *EdCaN* project and *Cancer Learning* in the use of on-line tools as an effective way of reaching health professionals. This has contributed to various NCGC workforce development initiatives, for example, *Development and Implementation of a Professional Development Package for General Practitioners/Health Professionals* and the *Psycho-sexual Care Module*.

The NCGC has contributed funding to the *Priority-driven Collaborative Cancer Research Scheme* (PdCCRS) with its research investment being extended through the ability this scheme offers for joint funding of research initiatives by several organisations with a common interest in the research outcomes. This has had the added benefit of these research grants being managed by the research and data team within CA who have a pre-existing relationship with the NHMRC and specific skill and experience in this complex area.

The NCGC has supported initiatives of CA, through funding several projects with a gynaecological cancer focus through the *Building Cancer Support Networks* initiative. There has been reciprocal learning, with the lessons learned by the NCGC applied by CA in the development of the recently funded *Lung Program*. The *Lung Program* is already planning to reach disadvantaged groups through partnerships with the NACCHO and FECCA.

Within the NCGC there are additional examples of how projects are leveraging off each other. For example, the *Psycho-sexual Care On-line Training Module* that is being developed will try to work with the jurisdictional workforce projects (implementing the *National Gynaecological Cancers Service Delivery and Resource Framework*) to pilot test the module. This engagement will be facilitated by the NCGC personnel.

4.2 How Did It Go?

The impact of the NCGC program will be evaluated by answering the question, 'How did it go?' across the three levels of the evaluation framework: Level 1 - consumers (cancer sufferers, families, carers, friends, communities); Level 2 - providers (professionals, volunteers, organisations) and Level 3 - the system (structures and processes, networks, relationships).

It is not possible to evaluate whether the NCGC has improved outcomes for women with gynaecological cancers, their carers and families. These types of changes require extended timeframes and sophisticated research designs to appropriately capture attribution. The NCGC has not been operating long enough or been funded to the extent required to generate tangible and widespread health improvements at this stage.

This section of our report presents our major findings as they relate to the impact of the NCGC.

4.2.1 Appropriateness

We have assessed the appropriateness of the NCGC Work Plan and the level of alignment between organisational priorities and the strategic intent of the Senate Inquiry,¹⁷ which led to the

¹⁷ Parliament of Australia, Senate Standing Committee on Community Affairs (2006) *Breaking the Silence: A National Voice for Gynaecological Cancers*. Commonwealth of Australia, Canberra.

formation of the NCGC.¹⁸ Our review of the Senate Inquiry recommendations and the response by the Department identified key priority areas for action by the NCGC. The multiple projects in train all align with the recommendations from the Senate Inquiry deemed to be the responsibility of CA.

There are many players in the cancer control arena at both the government and non-government level and in terms of consumer and professionally based organisations. From the outset, the NCGC was not expected to address gynaecological cancer issues across the full spectrum of the patient journey. For example, whilst the NCGC clearly supports Australian Government policy relating to cervical cancer screening, it is not responsible for policy or programs in this area, this rests with other Divisions within DoHA.

The NCGC has managed to spread its limited resources across a range of areas thereby ensuring that it is implementing projects relevant to consumers, the gynaecological cancer workforce and health professionals. In addition, it has initiatives that are designed to improve the evidence base for control of gynaecological cancers. There is strong evidence that the approach that the NCGC has taken to building collaborative partnerships in the delivery of all aspects of its operations, has been successful.

Evidence of Health Need

Another accepted way of judging the appropriateness of government programs is to ensure that there is still evidence of health need. The Senate Inquiry report, released in 2006, drew on a range of data produced mostly by the Australian Institute of Health and Welfare (AIHW). This data demonstrated the impact of gynaecological cancers on the health outcomes of Australian women and analysed data on incidence, projections, deaths and survival rates for women with gynaecological cancers.

A review of the AIHW web-site has been completed to identify any relevant publications released since December 2006. Whilst significant health gains have been made in some types of gynaecological cancers, (notably cervical); uterine, ovarian, vulval, vaginal and other gynaecological cancers continue to represent a significant disease burden for Australian women. As the population continues to age, Australian women will have an ongoing need for appropriate prevention, screening, diagnosis, treatment and supportive care. Within the Australian population, women in low socioeconomic groups have a higher incidence, as do Aboriginal and Torres Strait Islander women. Ovarian cancer remains of significant concern due to the high mortality, non-specific symptoms and the absence of screening and early detection measures.¹⁹

Comparative National Approaches

Our evaluation of the NCGC recognises the context of gynaecological cancer control within Australia. An understanding of this Australian context can be enhanced through comparing what is happening nationally with international gynaecological cancer control efforts in the USA, United Kingdom, New Zealand and Canada. The NCGC has a similar focus to comparative international approaches to gynaecological cancer management.

In summary:

- In recent years there has been a push internationally, to develop coordinated national strategies for cancer control. Gynaecological cancers may or may not have had much focus under these strategies, depending on the particular national context.
- The international comparisons indicate there has been a combination of government lead and partnership approaches to cancer control. Canada has taken a partnership approach that is largely independent from government. The benefits of this latter approach have been broad with high level engagement of cancer organisations supporting a comprehensive array of cancer control activities.

¹⁸ Parliament of Australia, Senate Community Affairs References Committee (2007) *Commonwealth Government Response to the Committee's Report, Inquiry into Gynaecological Cancer in Australia*. Commonwealth of Australia, Canberra.

¹⁹ AIHW (2010) *Ovarian Cancer in Australia: an overview, 2010*. Available at: <http://www.aihw.gov.au/publications/index.cfm/title/11158>

- The need to develop a coordinated approach to gynaecological cancers is evident. While there is a universal effort in the area of cervical screening and detection and treatment of cervical cancer, the effort towards reducing other gynaecological cancers is mixed. There is a strong focus in the area of ovarian cancer research, treatment and support with endometrial and uterine cancers also retaining some focus. There is scope for drawing the different strands together to provide a united effort in research, prevention, detection, treatment, support and professional development of the cancer workforce.
- The development of standards relating to gynaecological cancers is a step towards a united effort against these diseases. The only country in which this was evident was in the UK. Other countries tended to have separate standards for different gynaecological cancers.
- There has been recognition in the international community of the disparities in the impact of cancers, including certain gynaecological cancers, for indigenous communities and low socioeconomic groups. This has been a benefit of a national approach to cancer control, including national cancer surveillance initiatives. Of particular interest is the New Zealand approach to incorporating a focus on indigenous issues and needs in every aspect of its National Action Plan and the US work in helping indigenous nations develop their own strategic cancer control plans.
- Evaluation of pilot projects and programs is evident but evaluation at a national or strategic level is not. There are, however, examples from Canada in the area of lung cancer and tobacco control, of how an outcomes-focused, evaluable plan can be developed and implemented.
- Consistent parallels can be identified between international efforts at gynaecological cancer control and the approach of the NCGC. This means that the focus of the NCGC Work Plan reflects the aims of similar efforts in other Commonwealth countries and the US. This is not surprising as the agency priorities were informed by the Senate Inquiry that had canvassed issues and responded to submissions at a national level from key stakeholders in gynaecological cancer and from the input of the NCGC Advisory Group, which includes a diverse range of experts in this field.

4.2.2 Efficiency

Efficiency in the context of government program delivery can be considered as a 'measure of how economically resources/inputs (funds, expertise, time etc.) are converted to results'.²⁰ The aim is to either minimise inputs for a given level of outputs, or to maximise outputs for the given level of inputs.²¹

Internal Processes

Our initial discussions with NCGC personnel resulted in the identification of three key internal processes that are fundamental to the efficiency of the NCGC. These are: the coordination of the Advisory Group; procurement of third parties to implement activities on behalf of the NCGC and the process of grant management; to ensure that funded activities or projects are implemented efficiently and effectively.

The Advisory Group has already been addressed in Section 4.1.3. The NCGC derives high value from its investment in the Advisory Group. The members provide their time essentially at no cost, with only their travel expenses re-imbursed. There are relatively high costs of participation for members engaged in private practice/employment in foregone earnings. In return they provide a depth and breadth of expertise that the NCGC could not afford to buy-in. Their specialist knowledge is frequently used to inform project deliverables, particularly when there is a substantial clinical component to the project, for example, *Development and Implementation of Clinical Practice Guidelines for the Management of Women with Endometrial Cancers*. This needs to be

²⁰ Markiewicz, A. (2010) Monitoring and Evaluation Core Concepts (Unpublished Seminar Paper)

²¹ Commonwealth of Australia (2008) Review of Lapsing and Terminating Programmes/ Measures - Generic Terms of Reference (Internal correspondence to Cancer Australia from the DoHA).

recognised, either through remuneration or acknowledgement in relevant publications and or professional arenas.

In its early days, the NCGC relied on a contracting model for project delivery. This led to the Centre facing significant procurement challenges. In hindsight, the decision to outsource the procurement function did not deliver the anticipated benefits. As the NCGC was not widely known, at times it had difficulty in attracting a wide field of respondents to its tenders. Several lead NCGC projects required quite specific expertise which was difficult to acquire through the tender process. The NCGC is bound by the procurement processes of the Australian Government and through CA is subject to a high level of scrutiny and regular audits. It should continue to explore alternative models like a commissioning model. Service agreements with a smaller number of the most useful consultants would allow direct sourcing from those who have the necessary skills and technical expertise in this field. Within the framework of government, other options can be explored, such as the establishment of expert panels. There may be value in the NCGC implementing certain projects 'in-house' where clinicians with specific expertise in gynaecological cancers are paid to provide the technical advice needed e.g. development of clinical guidelines would be one example.

The NCGC spends a large amount of effort in administering grants and overseeing project delivery and it does this efficiently and effectively (refer to Section 4.1.1). Where possible it has worked with other organisations to facilitate this for specific projects including: the National Health and Medical Research Council (NHMRC), Winston Churchill Memorial Trust, Commonwealth Scientific and Research Organisation (CSIRO), NBOCC and CA. These arrangements have worked well in most instances; the major exception has been the experience with the *Consumer Fellowships* administered through the Winston Churchill Memorial Trust.

The NCGC has also effectively used partnerships to extend its reach and improve efficiency, (this has already been described in Section 4.1.4).

There is clear support and appreciation for the staff of the NCGC. Stakeholders consistently reported positive experiences with these staff and commented on their willingness to co-operate and collaborate and discuss issues as projects progressed.

The comment below is reflective of the predominant experience:

'I found that for me it felt very much like a partnership...I found them very responsive to trying different things and to actually, being in a sense part owners in that whole process of development for this.' (Stakeholder Interview, 2010).

Financial Management

Another measure of efficiency relates to the NCGC's capacity to efficiently distribute its budget in accordance with its objectives. The agency receives a relatively modest funding allocation of \$1.7M per annum. This allocation funds any related project delivery costs and the 2.1 FTE staff who work within the NCGC. The NCGC has been effective in ensuring full utilisation of this budget in 2008/2009. It is currently on track to achieve this same outcome for 2009/2010.

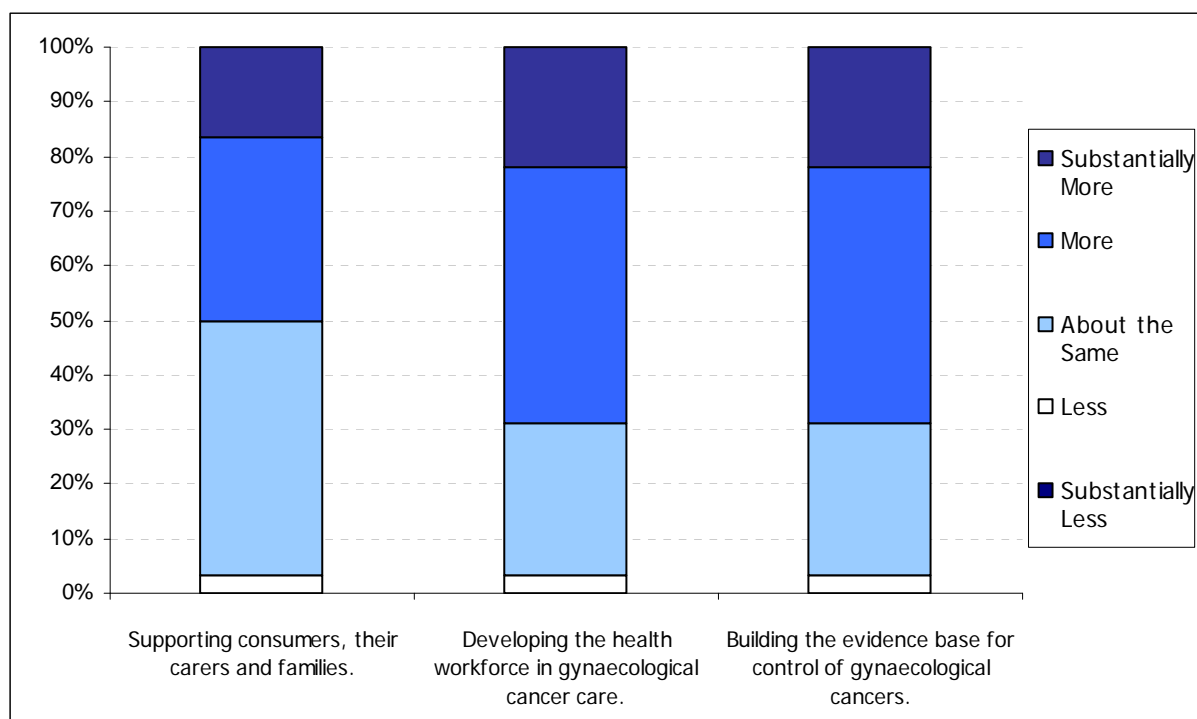
A simple analysis of project expenditure apportioned against each NCGC key objective demonstrates that the highest level of investment is occurring in projects focused on building the capacity of the health workforce, this is followed by initiatives that aim to build the evidence base for gynaecological cancer control with comparatively less investment in improving information and supportive care for consumers and carers. The purpose of this analysis is to map effort (expressed by project activities) against investment (expenditure).

In the on-line survey respondents were asked their views on the current distribution of NCGC resources across these key objectives. The distribution of responses for resource allocation in 'Developing the health workforce in gynaecological cancer care' and 'Building the evidence base for control of gynaecological cancers' were exactly the same. Almost 70% of respondents believe

more or substantially more resources should go into these areas, while only one respondent (making up 3.1%) believes less resources should be allocated.

In regard to resource allocation in ‘Supporting consumers, their carers and families’, 50% believe there should be more and almost 50% believe it should remain the same. This reveals that the respondents are more satisfied with resource allocation in this area.

Figure 4 NCGC resource allocations



The NCGC has aimed to ensure an appropriate balance of investment across the ‘required changes’ and ‘system enablers’ described in the program logic in Section 3.3. There are several possible ways to think about this, the balance of investment in terms of:

- economics (expenditure)
- effort
- focus

Whilst the aim was to allocate a third of resources to each of the three key objectives of the NCGC, in practice higher investment has occurred in the development of workforce capacity and building the evidence base for control of gynaecological cancers, as opposed to improving information and supportive care for women with gynaecological cancers, their carers and families.

4.2.3 Effectiveness

Effectiveness describes the extent to which outputs and/or administered items make positive contributions to the specified outcome. Effectiveness indicators are used to assess the degree of success in achieving outcomes.²² One of the major ways of assessing effectiveness is to evaluate the extent to which the program’s objectives have been, or are expected to be, achieved.

Overall Performance

The on-line survey found that 86% of respondents believe the NCGC does do things well. Key successes included:

- building and improving collaborations between organisations and stakeholders

²² Commonwealth of Australia (2008) Review of Lapsing and Terminating Programmes/ Measures - Generic Terms of Reference (Internal correspondence to Cancer Australia from the DoHA).

- engaging consumers and providing them with support, information and involvement
- networking the clinicians and researchers in the area.

With respect to whether there are things the NCGC should do better, 58% of respondents believe there is and only 8% believe there is not, the remainder are unsure. Suggested areas for improvement included:

- communicate more effectively with stakeholders
- organise and maximise use of resources
- maintain key focus and aims
- raise the profile of the NCGC
- gain a much stronger knowledge of the field.

Exactly half of respondents believe that continuing as is will lead to the NCGC achieving its goal of improving the health outcomes of women with gynaecological cancer, their carers and families. This left 23.3% who think that a change in priorities is necessary.

Some of the suggested areas for additional focus include:

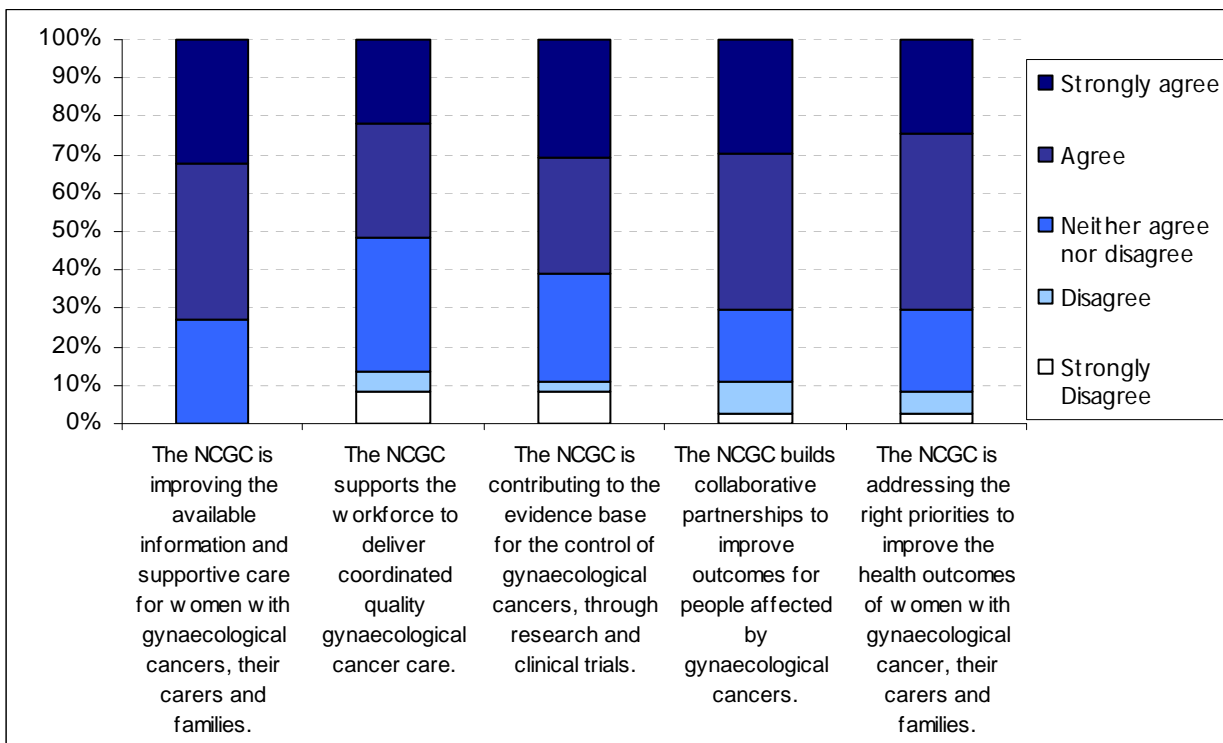
- increase preventable strategies
- enhance awareness about gynaecological cancers
- increase collaborations to help improve such things as health outcomes and innovative models of care and
- unite groups across States.

Figure 5 below displays the opinions of stakeholders to five statements concerning the NCGC. These statements are based on the key objectives of the NCGC and aim to illustrate stakeholder views as to the effectiveness of the NCGC in addressing these objectives.

The most notable feature is in the first bar corresponding to the improvement of available information and supportive care for women with gynaecological cancers, their carers and families (i.e. consumers). Not one respondent disagrees or strongly disagrees with this statement. In the other four statements in Figure 5 there is a portion of respondents who expressed some form of disagreement. The statement exhibiting most disagreement (and neutrality) relates to the NCGC supporting the workforce.

The remaining responses are reasonably similar to each other with a large majority of agreement amongst the respondents. The statement referring to how the NCGC contributes to the evidence base, for the control of gynaecological cancers through research and clinical trials, has three respondents that strongly disagreed.

Figure 5 Effectiveness of tasks undertaken by the NCGC



On-line survey participants were asked to rank a series of statements relating to the effectiveness of the NCGC.

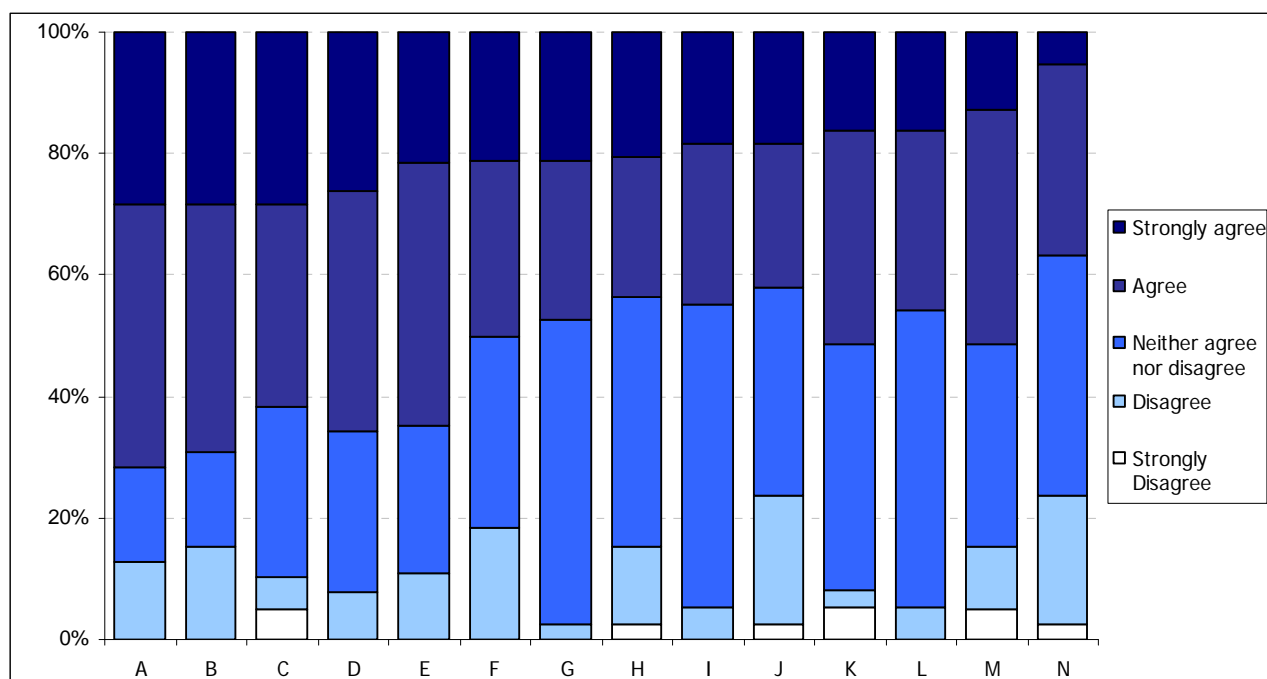
The overall impression conveyed in Figure 6 is mostly of agreement or neutrality of the provided statements. Statements J and N had the largest proportion of disagreement (including strong disagreement) with a proportion of 23.7% for both items. This means that respondents feel that the NCGC has difficulty selecting the right contractors/service providers to implement projects.

Statement N ‘The NCGC is trying to address too many demands’ also has the lowest proportion of agreement. This is to be expected as Statement N is the only negative statement out of the fourteen. This would suggest that there is not strong belief that the NCGC is trying to address too many demands, within the pool of survey respondents.

The statements with highest level of agreement come from A and B suggesting that the majority of respondents believe the NCGC is consulting well with stakeholders and they are satisfied with their own involvement. All the other statements also have a substantial amount of strongly agrees and agrees, but to a slightly lesser extent.

There are several noteworthy associations observed between responses to certain statements in this part of the survey. Firstly, there is a very strong association between responses to statements F and K which indicates that building the capacity of the cancer control sector is also making a positive impact. Another strong association appears between statements A and C which would suggest the NCGC communicating effectively with the respondents is related to a higher satisfaction with their own involvement. (The full summary of survey results is included in Appendix 2).

Figure 6 Effectiveness of the role of the NCGC



- A I am satisfied with my involvement with the NCGC.
- B The NCGC consults well with stakeholders.
- C The NCGC has established effective ways to communicate with me.
- D The NCGC effectively establishes collaborative partnerships.
- E The NCGC sets the right strategic priorities.
- F The NCGC is making a positive impact in the cancer control sector.
- G The NCGC utilises its financial resources wisely.
- H The projects delivered by the NCGC provide important lessons for others in how to do things better.
- I The NCGC manages grants effectively.
- J The NCGC selects the right contractors/service providers to implement projects.
- K The NCGC builds the capacity of the cancer control sector.
- L The NCGC monitors outputs effectively.
- M The NCGC adequately disseminates information about the work of the Centre.
- N The NCGC is trying to address too many demands.

Overall, the respondents believe that NCGC is performing well. It is addressing its key objectives, fulfilling its role and implementing its activities effectively. Despite only being recently established, the general feedback strongly indicates that the perception of respondents is that the NCGC is bringing about a positive impact for women with gynaecological cancer, their carers and families. This is supported by such comments as:

'I think that the establishment and continuing development of the NCGC has been a very positive step towards informing and improving care for women.' (Stakeholder Interview, 2010)

'Well, I think it takes some years for things to demonstrate a difference and so it'll take time, but I think it certainly has had some very positive outcomes in terms of the work that's now coming to fruition, because it's only in this term really that things have really been building up.' (Stakeholder Interview, 2010)

Leadership and Coordination Role

The report of the 2006 Senate Inquiry, *Breaking the Silence: a National Voice for Gynaecological Cancers*, recommended that the NCGC be established, within the auspices of CA, to provide a national focus to gynaecological cancer issues. In addition the NCGC was to work with the National Breast Cancer Centre (as NBOCC was known at this time) to ensure a cohesive approach to improving gynaecological cancer.

The NCGC has found it difficult to establish a national identity and this leadership role. This is in part a reflection of the size and scale of the NCGC and its short life-span, (for example, in comparison with the Australian Cancer Council and the NSW Cancer Institute). It is also a result of the approach that the NCGC has taken to leadership.

'...it is far too small to claim leadership and coordination...I think you've got to have a certain size and you've got to have a certain ability to buy programs and to deliver on the needs of the community before you're seen as a leader and coordinator and I don't think the Gynae Centre has ever had the funding where it could approach that sort of status.'
(Stakeholder Interview, 2010).

The NCGC targets stakeholders as leaders and sees its leadership role is to bring partnerships together and build leaders 'out there', meaning in the field as opposed to within the Centre. This is a point of differentiation for the NCGC as they achieve leadership through collaboration. This style of leadership and the NCGC's approach to consumer engagement has produced by Australian Government standards, a unique partnership that has equally harnessed consumers and cancer professionals. The NCGC has recognised that there is a need to build collaborative leadership in the sector as opposed to 'shouting from the corner' and it has elected to do this through an influencing role as opposed to just 'doing' through project delivery.

There is an expectation amongst most stakeholders that the NCGC will monitor outcomes for gynaecological cancer patients and provide a focal point and potentially consolidation of gynaecological cancer issues. The consistent message is that they have started to make inroads in this area but have a considerable way to go in establishing national leadership and coordination.

'I think that it's making as good an inroad into it as they possibly could given the resources of which they had at their disposal, and they are getting a tremendous amount, at the moment anyway, of goodwill from the people that are associated with it and from beyond.'
(Stakeholder Interview, 2010)

'I think what is missing in a lot of cancers is national networks and I think they've tried to do something along those lines and I'd certainly give them a tick for that.' (Stakeholder Interview, 2010)

Objective 1: Improving information and supportive care for women with gynaecological cancer, their carers and families

Our assessment of the impact on consumers has been limited to those involved with the NCGC.

Consumers are critical in managing effective outcomes for gynaecological oncology patients and it is fortunate that they have played a pivotal role in the NCGC from the very beginning – the previous experience of CA with consumers has helped to increase this emphasis.

One of the NCGC's greatest successes has been engaging consumers in information resource development. A wide range of appropriate consumer information resources are now available on the web (over 70 items) – addressing the need of a 'one-stop shop' for provision of information on gynaecological cancers. These resources cover the spectrum of gynaecological cancers and there are plans to print selected items and make these available to generalist and specialist clinicians. A major limitation identified was the level of awareness of the web-site amongst consumers and clinical groups – if the NCGC it to achieve wide dissemination it will need to address this issue.

There is variable awareness of the *Gynae Centre Newsletter* within the stakeholders that were interviewed. Lack of awareness of the *Consumer Fellowships* amongst consumer organisations was a consistent finding. There may be improved up-take of this opportunity with increased direct marketing of the fellowship to relevant consumer organisations. Whilst there was general support for developing skills within consumers to improve their capacity to contribute to the NCGC, there were mixed views on whether this specific initiative would lead to capacity building and a contribution to the wider cancer control sector. As would be expected this was not the view of consumers:

'I know we still need the academic and professional level, but it's not balanced, it's a bit like your Centre, it can't be balanced if you don't have the health consumer voice in amongst it.'
(Stakeholder Interview, 2010)

There is an expectation that the NCGC will support carer and families of women with gynaecological cancers. This was particularly highlighted by consumers and consumer organisations as an issue as gynaecological cancers were seen to have an immediate impact on the family, worsened by the fact that often gynaecological cancers present late and so the impact is immediate and significant. The optimal way for the NCGC to do this was seen to be through the establishment of frameworks and networks that all organisations can link into. There was not a view that the NCGC should be a support organisation but rather facilitate this through other agencies.

'...they're not going to get changes made unless they get consumers involved because it's the consumers who can provide the grease to turn the rusty wheel. So I mean as I said I think at the outset that they need to be congratulated in their involvement with consumers from day one.' (Stakeholder Interview, 2010)

Consumers found value in being involved; they were respected and did not feel under pressure to participate if they did not want to. Several referred to the process of applying to be a consumer with the NCGC and the value in this formalised approach.

'I feel I'm getting satisfaction because I 'm able to say something. Now moving forward and I've seen some of the reports and I've seen some of the comments that have been made and my contributions have been acknowledged, not just mine but others as well...'
(Stakeholder Interview, 2010)

The *Development of the National Gynaecological Cancers Service Delivery and Resource Framework* was cited as a good example of an initiative that had a genuine approach to ensuring womens' needs informed the framework development. This project recruited and formed a consumer reference group with ten women across Australia who teleconferenced on a monthly basis. This project also provided a good example of the NCGC's readiness to engage with conversations about change and improvement.

'I'd been dealing with gynaecologists but I didn't know a gynaecologist cancer expert existed and had I been given that knowledge, well, then I would have been able to say, "Look, I've got cancer in the family and I would like to see such a person"...but as a health consumer you don't know that stuff...' (Stakeholder Interview, 2010).

Objective 2: Supporting the workforce to deliver coordinated quality gynaecological cancer care

The NCGC has achieved a range of outputs in workforce support. The *Clinical Research Fellowships* are up and running with high calibre applicants. The first *Fellowship* is in train and selection is proceeding for the next recipient. There needs to be additional requirements for recipients to disseminate their learnings built into the funding agreement.

In 2007/2008 the NCGC worked with the RACGP to develop an on-line training module for patients referred to as: *The Female Cancers and Psychosocial Care Active Learning Module*. It has been designed to improve primary care management for women diagnosed with a malignancy. The learning tool has been available for over a year, on the RACGP's online education portal, gplearning, at www.gplearning.com.au.

This activity included a range of partners: the RACGP, CA, NCGC, Centre for Innovation in Professional Health Education and Research (CIPHER), University of Sydney, Medical Defence Australia (MDA) National and The Cancer Council of Australia. The activity has been approved for Category 1 points in the *RACGP Quality Assurance and Continuing Professional Development Program* and also for Women's Health points. Since its launch, approximately 300 GPs have accessed this module. Whilst the module includes learning objectives, it does not have an on-line evaluation component that could provide data on the impact of this initiative on GPs attitude, knowledge or behaviour.

The development of the *National Gynaecological Cancers Service Delivery and Resource Framework* in collaboration with RANZCOG represents the major workforce project for the NCGC. It has only recently been developed and *interjurisdictional projects* to implement relevant elements of the framework are in their infancy. The NCGC has engaged *Siggins-Miller to Support Coordination and Evaluation of Jurisdictional Projects*. The jurisdictional projects and *Framework* development and evaluation are the largest investment by the NCGC in any project area. This investment is aimed at supporting the workforce to deliver coordinated quality gynaecological cancer care. This project provides an excellent example of how the NCGC has leveraged off previous work by CA through using lessons learned in the CanNET initiative. Several States and Territories have co-located personnel working on CanNET with those addressing the *Framework* priorities.

The NCGC is well advanced in the development of an interactive on-line module on *Psycho-sexual Care* for women with gynaecological cancers. The target group includes health professionals in all sectors from GPs, primary care professionals through to specialists who work in the field, including nurses and allied health professionals. This has been identified as a real gap in the care of women and the module aims to equip the health workforce to better address this neglected issue. The focus is upskilling the workforce in something that's not done well. The identification of this gap came from the NCGC informed by the established knowledge in the field, literature and was very much driven by consumers. This module has tried to address diversity and the needs of disadvantaged women. Some of the content addresses the skills and capabilities that health professionals need, working across cultures. The project working group structure provides a way of engaging specific target groups in the development of the module. In this instance there is good representation from the Australian College of Rural and Remote Medicine (ACRRM). A process of peer review has been used to engage clinicians and service providers and consumers from diverse backgrounds. The design features have been improved through advice and feedback from likely users along the way. In this project the Working Group has been a valuable source of technical advice.

Objective 3: Building the evidence base for control of gynaecological cancers, including through research and clinical trials

A range of projects have been completed and are in progress that have the capacity to build the evidence base in the field of gynaecological cancers.

The NCGC uses the *Priority-driven Collaborative Cancer Research Scheme* (PdCCRS) as a vehicle to administer their research. The NCGC is a funding partner in this scheme. In 2008 the NCGC started the process of identification of research priorities; the first round was funded in 2009 and the round for 2010 is currently at the stage where the applications are under assessment and offers of funding will be made in November 2010.

The NCGC research priorities were vetted by the National Research Advisory Group and the National Consumer Advisory Group of CA. There is a clear link between the nominated priorities and the known gaps in the evidence base. The NCGC Research Working Group initially assisted by 'framing' the priorities internally, applications were then sought through the CA research funding process. This group and representatives of the NCGC and CA used the 2007 *Audit of Cancer Research* (previously completed by CA) to inform the selection of priorities. All projects are administered by the research and data team of CA on behalf of the NCGC as this team has specific expertise in ongoing research grant management.

The advantage of using the PdCCRS process is that all grants are reviewed through the NHMRC and this ensures application of their 'gold standard' in terms of assessing the quality of the research and the capacity of the research applicant. Questions additional to those required by the NHMRC are included by CA/NCGC. These additional questions address issues such as partnerships, impacts and outcomes, research translation into policy and practice and consumer involvement. These applications are reviewed by CA via a grant review panel which has three members of the funding organisation, one consumer trained in research grant review, one CA officer and one NHMRC officer.

The NHMRC application component is weighted 40% and the CA application component is weighted at 60% - this ensures that all research grants awarded are strictly merit based. Another advantage is that because of this review rigour, these grants attract Category 1 funding as they are endorsed by the NHMRC and consequently they attract infrastructure funding.

In addition, use of the PdCCRS provides the NCGC access to co-funding opportunities as different funding partners may have an overlap in funding priorities and can agree to jointly fund an application. This allows the NCGC funding to be spread across more research projects and supports the development of new partnerships.

No research outcomes have been generated yet. The first round (or 2009 grants) was funded from the beginning of 2010 and the first annual report is not due until the end of 2010. Most projects are funded for two to three years. The funding emphasis of the PdCCRS has been on patient centred research that has direct application to patient treatment and care.

The NCGC research in essence has just been funded and given that the aim is to increase the evidence base, a KPI will be the publications and presentations that flow from this research. CA monitor this but don't stipulate this as a requirement of research funding as these outputs are part of the established 'research culture' and are a key pre-requisite for researchers to attract further funding in the future. There may be value in formalising this understanding.

The *Analysing Patterns of Referral for Women with Gynaecological Cancers project* had two parts, the development of survey instruments and the implementation of a national survey of gynaecologists and GPs looking at their referral practices for women with gynaecological cancers. This was conducted as a mail survey with an on-line option using a group of vignettes or stories that clinicians had to respond to and aimed to establish the key factors influencing referral. These projects have identified the need for developing Australian evidence based guidelines for vulval and endometrial cancers. The *Development of Clinical Practice Guidance Materials for the Management of Women with Endometrial Cancers* is in progress. This has been a challenging project and there have been delays due to issues with the contracted supplier. The NCGC is currently resolving a way forward, using the knowledge and expertise of its partners.

Several stakeholders expressed concern at potential duplication, particularly in the area of clinical guideline development.

'For a Centre like this you need to link strongly with the clinical groups and I think that the NBOCC had forged a considerable path in that area and linking with clinicians and performing and preparing guidelines and documentation that could be translated to other cancers. So perhaps there's been a bit of doubling up and a bit of duplication.'
(Stakeholder Interview, 2010)

'...we work at both the jurisdictional and national level; there is much too much duplication across the board. Health resources are scarce, funding is scarce and...well I'll just say that.' (Stakeholder Interview 2010)

The NCGC has had limited reach to date in terms of distributing service provider resources, this is set to change in the next year as the outputs become available from the *Psycho-sexual Care*

Module; Development and Implementation of Clinical Practice Guidelines for the Management of Women with Endometrial Cancers; Development and Implementation of Minimum Data Sets for Ovarian, Cervical and Endometrial Cancers – including Surgical Synoptic Reporting etc. These latter projects have provided an opportunity to collaborate with NBOCC.

Objective 4: Building collaborative partnerships to improve outcomes for people affected by gynaecological cancers

The NCGC has developed a genuine and effective approach to collaboration. This is reported as one of its key successes.

It has good partnerships in place with professional associations, consumer organisations and jurisdictions that support project delivery. Projects in all areas are likely to strengthen existing networks and relationships and establish new ones. This has been discussed in detail in Section 4.1.4. Sustaining these partnerships will require ongoing investments in communication and joint project delivery.

4.3 Can You Keep It Going?

There are divided views as to the sustainability of the NCGC as an organisation. The recently announced merger between CA and NBOCC is generally seen as a positive step.²³ The sustainability of the NCGC was consistently raised throughout the qualitative interviews and in comments in the on-line survey. It was identified as the most important strategic issue facing the organisation.

Key stakeholders recognise the time limited funding of the NCGC and the restrictions imposed by the size of the NCGC budget. There is also recognition of the potential for overlap and duplication with the NBOCC, as both agencies share responsibility for improving health outcomes for women with ovarian cancer.

Multiple views arose from our data: the NCGC should merge with NBOCC, this new entity could be rebadged as a national women's cancer centre. The NCGC should be absorbed by NBOCC and cease to exist as a separate centre. The NCGC should continue to stand alone and work to better establish its profile and identity. The NCGC should be restructured as a program within Cancer Australia allowing a specific focus on gynaecological cancers but without the designation of a Centre. The responsibility and funding associated with ovarian cancer control should be transferred from NBOCC to the NCGC and NBOCC would continue with a focus solely on breast cancer etc. There is a view that no-one is well served by having gynaecological cancer so fragmented.

'...what happens to gynae is really a subset of the bigger picture of how the government is going to rationalise its cancer agencies.' (Stakeholder Interview, 2010)

Whilst one view may not have prevailed, there were two consistent messages. Firstly, the NCGC should continue but it is time for the structure of the NCGC to be revisited. Secondly, there would be benefits of joining the ovarian cancer component of NBOCC with the NCGC component. National direction for gynaecological cancers needs to be brought together as this might lead to increased use of scarce resources and reduction of potential for duplication. In addition, the NCGC should continue to reap the benefits of being part of CA irrespective of its governance structure.

A distinction was made by stakeholders between public positioning vs. program efficiencies. It does not appear to matter whether the NCGC is run as a Centre or program in terms of operational efficiencies. However, at the time of its establishment there was certainly more of a political imperative for the NCGC to be seen as a Centre. This feeling is not as clear cut in 2010.

²³ Media Release 'One Single, United and Stronger National Cancer Agency' issued by The Hon Nicola Roxon MP, Minister for Health and Ageing, 15 June 2010. Accessed 16 June 2010 at <http://www.canceraustralia.gov.au/media/files/ca/Media%20release%20Amalgamation.pdf>

At the operational level, the issue is the sustainability of the direct improvements or lessons arising from projects that the NCGC has funded and the sustainability of the approaches learnt as part of the broader program (consumer engagement, partnership development etc.). Evaluation of sustainability is closely aligned with the issue of capacity building (e.g. increased capability and skills, increased resources) and any changes in structures and systems that 'anchor' or embed changes and facilitate sustainability.

Projects are funded for time-limited periods in accordance with the budget cycle. In several cases, projects were developmental in nature and contributed to a future output. A case in point is the *Review of the Gynaecological Workforce* completed by the National Institute of Labour Studies (NILS). This project resulted in an output that has informed the development of a subsequent project, the *Development of the National Gynaecological Cancers Service Delivery and Resource Framework*.

Another example is the initiative *Analysing Patterns of Referral for Women with Gynaecological Cancers – Development of Survey Instruments* and the *Referral Survey of GPs and Gynaecologists*. Both of these projects represented a considerable investment of effort and resources. These projects were 'once-off' initiatives which produced deliverables that have informed a further project *Development and Implementation of Clinical Practice Guidelines for the Management of Women with Endometrial Cancers* and the knowledge gained relating to referral practices is also being incorporated into the *Development of the National Gynaecological Cancers Service Delivery and Resource Framework* and *Psycho-sexual Care Module* currently under development.

In short, these projects were never intended to be sustainable but served as a means to an end. The rate-limiting factor for all projects however is the availability and continuity of funding for the NCGC cannot allocate funds beyond its budgeted three year funding cycle. There is an ongoing need to develop the capacity of the NCGC personnel if more 'in-house' project delivery is required and lessons learned must continue to be shared throughout CA.

'I believe that the model of having programs of work under the auspice of Cancer Australia is the only way that we will get sensible and sustainable system change. I think because the learnings will be coherent and used in other kinds of settings as things move forward but will also get some uniformity about what is being advocated.' (Stakeholder Interview, 2010)

Inter-jurisdictional partnerships and engagement with professional associations provide the best chance for sustainability of selected interventions.

'I think effective frameworks for service delivery that can be adapted to local needs so that we're not thinking about a "one size fits all" solution for the whole country would be useful outcomes.' (Stakeholder Interview, 2010)

4.4 What Has Been Learned?

The NCGC has built capacity in several ways. Its key successes have been the approach that the Centre has employed to engaging consumers and the development of collaborative partnerships to improve outcomes for women affected by gynaecological cancers, their carers and families. The NCGC has built capacity in both consumers and service providers and its own personnel through their shared experiences in project working groups. They have developed or are in the process of developing resources for both consumers and service providers and have contributed to building the evidence base to improve professional practice. The investment in on-line learning modules and the capacity building of the workforce through the *National Gynaecological Cancers Service Delivery and Resource Framework* has not yet demonstrated an impact – these initiatives, once implemented, are likely to build workforce capacity.

The commitment to working with consumers in an equal and meaningful way is a hallmark of the 'Cancer Australia' approach. The NCGC has used the skills within CA in consumer engagement.

It has learned from past experiences within its parent organisation and applied this knowledge in an effective manner. The NCGC has been able to recruit appropriate and trained consumers to its Advisory Group and project working parties. The commitment to ensuring the ongoing growth of consumers is seen through the funding of the *Consumer Fellowships*.

The NCGC is one part of a broader cancer control and health care system. It operates under the auspice of CA which in turn operates within the Australian Government policy framework endorsed by DoHA. The Commonwealth is not a provider of health care, this remains a State responsibility and whilst the recently proposed health care reforms may lead to some changes, States will continue to be responsible for providing hospital care.

It has been very difficult to engage jurisdictions around gynaecological cancer because of the low incidence, which has contributed to a desire to mainstream management of these cancers. The NCGC has maintained a position that there is a need for specialised services to effectively manage gynaecological cancers. The NCGC recognises the inherent conflict between geographical access and specialisation which is a feature of Australian health care because of our geography. The development of the *National Gynaecological Cancers Service Delivery and Resource Framework* recognises this tension and aims to support the view that quality care means specialisation and travel for women with these types of cancers. This means the NCGC has a role in 'limiting expectations' of what is possible for both women and clinicians. Fortunately, CA has a role in stating which cancers require quaternary care – this should help access to quality care and treatment in the right place.

Working with other jurisdictions requires flexibility. This has not meant compromising standards or frameworks but recognising that there will be different resources and levels of support in jurisdictions. Sometimes this means deliberately investing time and resources where the Centre is likely to get the biggest impact, and recognising when the timing just may not be right, for a whole range of reasons, in different jurisdictions.

4.5 Are Your Lessons Useful for Someone Else?

The approach that the NCGC has taken to managing gynaecological cancers could potentially be a model for other cancers, through CA. The NCGC has acquired substantial methodological knowledge that is being fed back into CA. The internal synergies within CA across other programs provide an important contribution to generalisability.

The lessons learned in improving outcomes in gynaecological cancers have wide-spread applicability across other cancer programs. The proposed reorganisation of CA appears to recognise synergies between the NCGC and broader work of CA.

4.6 Who Did You Tell?

Dissemination can be achieved through:

- dissemination of products or outputs from projects
- dissemination of process learning and ideas that could be adopted by other sectors
- dissemination of work of the NCGC relevant to other settings.

The NCGC has more to do in terms of disseminating its outputs and increasing its profile nationally. There has been inadequate resources for the promotion of the work of both the NCGC and CA. This lack of organisational capacity in communication and marketing should be redressed as more emphasis is needed.

Within the limits of available resources, the NCGC has tried to maintain a web presence with routine review of its web pages and regular checks of the functionality of web links. New content

is added as it becomes available, for example, such as the *Gynae Cancer Centre Newsletter*.²⁴ This electronic newsletter is issued once per year, there is an e-distribution list with approximately 70 addresses. The NCGC web-site provides a range of information on projects of the Centre and one of the most recent additions has been a suite of consumer information resources on gynaecological cancers which provides quality and reliable information relating to gynaecological cancers in Australia.

The NCGC web-page generally is the main mechanism for disseminating information on the work of the NCGC. It has not yet realised its full potential and requires ongoing investment. The development of a web monitoring system is a priority.

The NCGC could also make use of the *Cancer Learning* web-site to disseminate on-line training modules and resources. There may be potential to utilise some of the monitoring mechanisms established through this site.

The report of the Senate Inquiry, *Breaking the Silence*²⁵, recommended that:

'In all aspects of its work, the Centre should make optimal use of communications and information technology, including the Internet, to bring people together to discuss issues.'

The Commonwealth Government Response²⁶ was as follows:

'The Commonwealth Government agrees with this recommendation. The Government will ask the new Centre for Gynaecological Cancers to develop a strategic plan to guide its work which includes the development of a website and mechanisms to make optimal use of communications and information technologies to support information sharing on gynaecological cancer issues.'

In our assessment the NCGC has not made optimal use of communications and information technology. The introduction of a web-based monitoring system that will allow the NCGC to gather data on web-hits by topic of interest, email domain and geographical region should be promptly considered. This is particularly important given the recent release of the consumer information resources. There is no mechanism yet in place to monitor the dissemination of these resources via the web. An improved search function is needed. Currently there is no feedback mechanism to assess consumer or health provider satisfaction with the web

In the future the NCGC might promote the work of the Centre through professional colleges such as the RACGP and RANZCOG. Targeted relationships may also generate improved recognition within the clinical community. NCGC may work with partner organisations like RANZCOG to develop distribution mechanisms that will reach wider groups of clinicians. They have previously done this with the clinical guidelines project and sent a survey to 500 gynaecologists.

Projects like the *Priority-driven Collaborative Cancer Research Scheme; Clinical Research Fellowships and possibly Consumer Fellowships* have the potential to generate journal articles and/or conference presentations. The NCGC should be acknowledged as the funder of these outputs and this should be specified in these funding agreements/contracts. The project *Analysing Patterns of Referral for Women with Gynaecological Cancers – Referral Survey of GPs and Gynaecologists* has produced an article for publication in the *Medical Journal of Australia* and there are several other articles in progress. The NCGC should seek opportunities for joint authorship.

²⁴ Accessed 20 June 2010 at: <http://www.canceraustralia.gov.au/newsletter/gynae-cancer-centre-newsletter/gynae-cancer-centre-newsletter-july-2009>

²⁵ Parliament of Australia, Senate Standing Committee on Community Affairs (2006) *Breaking the Silence: A National Voice for Gynaecological Cancers*. Commonwealth of Australia, Canberra.

²⁶ Parliament of Australia, Senate Community Affairs References Committee (2007) *Commonwealth Government Response to the Committee's Report, Inquiry into Gynaecological Cancer in Australia*. Commonwealth of Australia, Canberra.

Representatives of the NCGC have presented at relevant conferences such as: the Clinical Oncological Society of Australia (COSA) Conference; RANZCOG Conference etc. and this should continue to be supported. Dissemination of information through health care providers is a useful strategy.

There are three areas where the NCGC could disseminate 'methodological' or 'how-to' information because of their developing capacity in: consumer engagement, collaborative partnerships and interjurisdictional engagement. These are areas in which the Centre has 'punched above its weight'. Any dissemination strategy must be developed and integrated with ongoing monitoring and evaluation strategies.

In summary

- The NCGC delivers a diverse range of projects efficiently and effectively. Most projects have been completed on time and with the agreed outputs.
- An ongoing challenge for the NCGC is ensuring appropriate monitoring and evaluation of its work that is consistent with the broader approach of CA.
- The Advisory Group adds considerable benefit. It is due to review its Terms of Reference. It may also benefit from some rejuvenation of its membership.
- The size and scale of the NCGC has led to a deliberate strategy of collaboration and partnership development to achieve the objectives of the Centre. There is strong evidence that this approach has been successful.
- Meaningful engagement has been a hallmark of the NCGC approach with consumers participating in all aspects of the Centre. Data consistently shows that consumers working with the NCGC feel their contributions are welcomed and uninhibited by the NCGC. Consumers reported the recent *Development and Implementation of Resources for Consumers and Health Professionals* as a particular success.
- Internally the NCGC has leveraged off the success of CA initiatives such as the CanNET project and *Priority-driven Collaborative Cancer Research Scheme (PdCCRS)*.
- The priorities of in the NCGC Work Plan align with the recommendations from the Senate Inquiry report *Breaking the Silence*.
- Gynaecological cancers continue to represent a significant disease burden for Australian women.
- The NCGC has a similar focus to comparative international approaches to gynaecological cancer management.
- The NCGC spends a large amount of effort in administering grants and overseeing project delivery and it does this efficiently and effectively.
- The NCGC has been effective in ensuring full utilisation of its budget in 2008/2009. It is currently on track to achieve this same outcome for 2009/2010.
- The highest level of investment is occurring in projects focused on building the capacity of the health workforce.
- The NCGC has found it difficult to establish a national identity and leadership role.
- The NCGC targets stakeholders as leaders and sees its leadership role is to bring partnerships together and build leaders 'out there', meaning in the field as opposed to within the Centre.
- A range of projects have been completed and are in progress that address the objectives of the NCGC.
- The NCGC uses the PdCCRS as a vehicle to administer their research. The NCGC is a funding partner in this scheme. No research outcomes have been generated yet.

- The development of clinical practice guidance materials for the management of women with endometrial cancers is in progress. Several stakeholders expressed concern at potential duplication, particularly in the area of clinical guideline development.
- The NCGC has had limited reach to date in terms of distributing service provider resources, this is set to change in the next year as the outputs become available from the *Psycho-sexual Care Module etc.*
- There are divided views as to the sustainability of the NCGC as an organisation. Firstly, the NCGC should continue but it is time for the structure of the NCGC to be revisited. Secondly, there would be benefits of joining the ovarian cancer component of NBOCC with the NCGC component.
- Inter-jurisdictional partnerships and engagement with professional associations provide the best chance for sustainability of selected interventions.
- The NCGC has built capacity in both consumers and service providers and its own personnel through their shared experiences in project working groups.
- The approach that the NCGC has taken to managing gynaecological cancers could potentially be a model for other cancers, through CA. The NCGC has acquired substantial methodological knowledge that is being fed back into CA.
- The NCGC has more to do in terms of disseminating its outputs and increasing its profile nationally. There has been a lack of resources for the promotion of the work of both the NCGC and CA.
- The NCGC is performing well. It is addressing its key objectives, fulfilling its role and implementing its activities effectively. Despite only being recently established, the general feedback indicates that there is a perception that the NCGC is bringing about a positive impact for women with gynaecological cancer, their carers and families.
- It is not possible to evaluate whether the NCGC has improved outcomes for women with gynaecological cancers, their carers and families. The NCGC has not been operating long enough or been funded to the extent required to generate tangible and widespread health improvements at this stage.

5 Implications for the National Centre for Gynaecological Cancers

The NCGC has an ongoing need to measure how it adds value and to determine what difference it makes. A major limitation for this evaluation was the lack of routinely collected data to support our assessment of the impact of the NCGC. As we identified at the commencement of the evaluation, there was adequate evidence to demonstrate project delivery but we have relied on qualitative methods to assess impact, capacity-building, dissemination, generalisability and sustainability.

5.1 Key Performance Indicators

The NCGC operates under the Key Performance Indicators (KPIs) set by the Australian Government. The *Health and Ageing Portfolio Budget Statements 2010-11*²⁷ document qualitative and quantitative deliverables and corresponding KPIs. For 2010-11 the NCGC's responsibilities are as follows:

Qualitative Deliverable: Manage and coordinate program activities that will improve information and resources, support the workforce and help build the evidence in gynaecological cancers.

The corresponding 2010-11 Reference Point or Target is: Program objectives achieved, for the coordination of the gynaecological cancer workforce initiative in collaboration with States and Territories by June 2011.

Quantitative Deliverable: Number of information resources published for women with gynaecological cancers, (with a specification of one within 2010-11).

Quantitative KPI: Percentage of States and Territories with specialist gynaecological services participating in at least one gynaecological cancer project, (with a 2010-11 Budget Target of 100%).

The NCGC requires a small suite of key performance indicators (KPIs) for future use. These may be monitored routinely by the Advisory Group over an extended period of time. These KPIs are predominantly driven by the established Work Plan of the NCGC. During the consultation process a range of KPIs were suggested (refer to Appendix 3). Several of the elements within the NCGC Gynaecological Cancers Service Delivery and Resource Framework will provide useful additional KPIs, this work is currently being undertaken by Siggins-Miller.

Outcome measurement will not be possible until a national database is established for treatment and clinical outcomes. This will be a costly exercise and require inter-jurisdictional co-operation. The *Development of the MDS and Pilot testing of Surgical Synoptic Reporting* represent first steps along this pathway. In the interim period, we recommend the adoption of KPIs that address core elements of the NCGC program logic.

If the NCGC implements projects that address the 'required changes' with appropriate and where possible evidence based strategies, then it is plausible that these interventions will lead to improved health outcomes for women with gynaecological cancers, their carers and families. If the Australian Government wants to improve health outcomes in gynaecological cancers then it will need adoption of this program logic beyond the NCGC.

²⁷ Commonwealth of Australia. *Budget: Portfolio Budget Statements 2010-11: Budget Related Paper No.1.11, Health and Ageing Portfolio*. C 2010. Canberra. Pp.604-607.

Table 3 *NCGC Key Performance Indicators*

Performance Domain	Key Performance Indicators
1. Projects	1.1 95% of projects specified in the NCGC Work Plan are completed on time and within the allocated budget by June 2011.
	1.2 100% of program objectives achieved for the coordination of the gynaecological cancer workforce initiative in collaboration with States and Territories by June 2011.
	1.3 100% of new project proposals have a demonstrable link to the NCGC program logic.
2. Governance	2.1 100% of the annual budget is expended within the allocated financial year in 2010-11.
	2.2 70% of Advisory Group members attend a minimum of two Advisory Group meetings per annum in 2010-11.
	2.3 Membership of the NCGC Advisory Group includes representation from every major State (Qld, NSW, Victoria, SA and WA) by June 2011.
3. Objectives	3.1 Number of information resources published for women with gynaecological cancers (with a specification of one within 2010-11).
	3.2 100% of States and Territories with specialist gynaecological services participate in at least one gynaecological cancer project in 2010-11.
	3.3 80% of States and Territories participating in jurisdictional projects relevant to the Gynaecological Cancers Service Delivery and Resource Framework agree to pilot test elements of the Psycho-sexual Care Module by June 2011.
	3.4 Number of partnership agreements developed for use with relevant women's health organisations (with a specification of one within 2010-11).
4. Required Changes	4.1 100% of NCGC on-line training modules applicable to General Practitioners are allocated CPD points from the RACGP by June 2011.
	4.2 Number and postcode of health professionals completing the on-line Psycho-sexual Care Module (with a specification of at least 25 within 2010-11).
	4.3 The NCGC web-site provides links to all NHMRC approved clinical trials relevant to gynaecological cancers by June 2011.
	4.4 100% of members of the RANZCOG will be provided access to clinical practice guidelines for the management of women with endometrial cancers by June 2011.
	4.5 Number of dissemination activities relating to the clinical research fellowship (with a specification of one within 2010-11).
	4.6 Establish a baseline for periodic assessment of womens' experiences of gynaecological cancer care using the NGCSDRF survey tool for women and carers by June 2011.
	4.7 Number of relevant women's organisations where at least one member has participated in a working group of the NCGC.
5. System Enablers	5.1 100% of research initiatives funded under the PdCCRS produce a research output suitable for dissemination within 2 years of grant completion.
	5.2 50% of research grants funded by the NCGC through the PdCCRS attract co-funding from another research partner
	5.3 Dissemination of a National Gynaecological Cancers Specialist Minimum Data Set and data dictionary to all States and Territories by June 2011

5.2 Conclusions

The NCGC has not delivered improved outcomes across cancer control, including primary care and the private and public sectors. This is to be expected given its short lifespan and limited resource base. It is however, mostly doing the right things that will plausibly influence the 'required changes' that lead to improved outcomes. Generating improved outcomes will be the result of many different factors, interventions and contributors.

It has been successful in working closely with all sectors and other stakeholders such as consumers and health professionals with its greatest achievements, its approach to consumer engagement and the establishment of active collaborative partnerships. It has delivered what it said it would, within acceptable timeframes and allocated resources. It has provided direct benefit to consumers associated with the NCGC and is poised to deliver genuine contributions to workforce capacity and the evidence base for control of gynaecological cancers.

The NCGC is expending almost two-thirds of its resources on developing workforce capacity. CA needs to define their role in the overall professional development space – it may be timely to explore different models and to develop capacity in partnership with the States and professional associations.

The NCGC needs to strengthen its relationships with clinicians, particularly gynaecology-oncologists. There need to be fair and reasonable professional rewards for their involvement in projects through appropriate forms of acknowledgement.

Finally, it is important that stakeholders recognise the advantages that accrue from the NCGC's organisational position. The direct connection it has with government provides opportunities for national action that have not yet been realised.

'I know that without the conduit to government you can really not make system change...'
(Stakeholder Interview, 2010)

'I actually think that by being a program within Cancer Australia as opposed to sitting outside, much more emphasis could be placed on the broader system reforms which will ultimately impact on all cancers not just gynaecological cancers.' (Stakeholder Interview, 2010).

The key strategic issues for the NCGC are its sustainability and the availability and quantum of ongoing funding.

'It has to have a war chest, for strategic investment. And you can create the rules for that strategic investment, which is it has to be done in partnership, it has to create change, it has to be focused on health outcomes, it has to be focused on increasing clinical capacity, and it has to be done in partnership with health service organisations. You can do all those things. But it is a war chest for change.' (Stakeholder Interview, 2010)

An unintended consequence of establishing the NCGC as a 'Centre' as opposed to a program is that this has raised huge expectations. Frequently stakeholders described their expectation was initially a bricks and mortar Centre as opposed to the virtual entity that was established. At times it appears that this has detracted from the work of the program.

'I think with the interest in the area, it's difficult to keep everyone sort of happy and to meet all the expectations. I think people in this area have such high expectations and they just really can't be met.' (Stakeholder Interview, 2010)

'...I think there is a need for defragmentation, coordination, strategic investment which has leverage attached to it to create changes.' (Stakeholder Interview, 2010)

In summary:

- There is evidence that the NCGC engages its consumers. The majority of survey respondents believe that consumers are benefiting from the work the NCGC does through their support and involvement with them. This appropriately aligns with the Senate Inquiry that led to the establishment of the Centre.
- The NCGC's ability to engage with all stakeholders and groups is effective and provides individuals and organisations purposeful ways to contribute to the NCGC. This strong engagement has created effective collaborations which contribute to the work of the Centre.
- There is an indication that although the collaborations are effective, the communication between certain groups can be improved. It is important to have cohesion between stakeholder groups as this supports achievement of the objectives of the Centre. There is a view that more work is needed to engage clinicians in the work of the Centre and develop workforce capacity. This is a pivotal relationship in terms of the sustainability of the NCGC.
- There are beliefs that as a national organisation the Centre requires more emphasis on inter-jurisdictional projects across Australia. These projects are central to the sustainability of major initiatives such as the *Development of the National Gynaecological Cancers Service Delivery and Resource Framework*.
- An area in specific need of improvement is the dissemination of information and creation of awareness about the NCGC. There are opinions that raising the profile is a very necessary component in the successful advancement of the Centre. As a recently established Centre it is understandable that the NCGC does not have a high profile, although this is something that can be built on in the future.
- There is a high level of personal satisfaction amongst those involved with the NCGC which is likely to be attributed by the high level of involvement they feel with the Centre.
- The greatest negativity in relation to the effectiveness of the NCGC comes from a belief that the operations of the NCGC are impeded by bureaucracy. These references to bureaucracy are about the 'machinery of government' as opposed to the day to day operations of the Centre. This is very clearly not directed at staff of the NCGC but at higher levels of government. Some stakeholders felt this trivialises their contribution.
- There is recognition and frustration at the limited resources afforded to the NCGC and that authority for expenditure ultimately rests with government.

In conclusion, whilst the evaluation has identified some areas for improvement for the NCGC, there are many positive and encouraging comments about the Centre and its activities. In our estimation the NCGC appears to be functioning effectively and progressing towards its future goals.

5.3 Recommendations

The following recommendations are provided for the consideration of the Chief Executive Officer of CA and the NCGC Advisory Group:

1. The NCGC should position itself as a leading example of national cancer program management.
2. The Advisory Group should be retained with revised terms of reference and a review of membership to ensure all States and Territories participate.
3. The program logic set out in this report should be reviewed, amended as necessary and used as a compass to assess new project proposals and direct KPI development. The objectives of the NCGC remain appropriate and relevant.

4. The NCGC should adopt a small suite of KPIs that are routinely reported to the Advisory Group. They will align with the requirements of DoHA and the priority areas where the Centre is aiming to have greatest impact.
5. Sustained efforts are required to address the needs of women with the poorest gynaecological health outcomes within the limits of available resources. These may be best implemented as part of a broader CA or Departmental strategy and include more emphasis on prevention and early detection.
6. The NCGC should explore alternative procurement models that comply with legislative guidelines but allow it to access appropriate clinical and technical expertise on an ongoing basis.
7. There should be wide engagement with key stakeholder groups over future priorities and the formulation of an annual NCGC Work Plan. The Work Plan should continue to be endorsed by government and align with available resources. These discussions should be supported by considering the latest available evidence.
8. All future project proposals should include a monitoring and evaluation plan that is resolved at the project design stage. This will ensure appropriate data collection to monitor the implementation and impact of projects. Evaluation should be periodic and may not be appropriate for smaller, short-term projects.
9. The NCGC should move toward three year grant funding projects for all research initiatives to align with the majority of other PdCCRS grants. This may result in a wider range of applicants and lead to more 'co-funding' opportunities as most other funders provide resources for a three year period.
10. The NCGC should investigate the potential to link its existing National Institute of Clinical Studies (NICS) fellowships to its research grants. For example, the NICS fellowships could be tied to implementing research findings that come out of the PdCCRS – this would lead to a continuum of effort. This also recognises that there are different skills required to research as opposed to effectively translate research into policy and practice.
11. The NCGC should continue to build the skill base of NCGC personnel in the field enhancing their understanding of gynaecological cancer and its impact on people, the current evidence base and critical appraisal skills.
12. Investment should be maintained in the training and support of gynaecological cancer consumers, their carers and families.
13. The NCGC needs ongoing investment in establishing and maintaining consumer and professional networks in the field. It may be useful to develop some partnership instruments to formalise these relationships. For example, working collaboratively with Medical Colleges in developing programs that attract Government start up funding, that engage health care professionals and can be implemented across the entire country.
14. The NCGC needs to continue to work to bring relevant organisations under one umbrella – providing strong and credible national leadership in a model that unites consumer, clinical and bureaucratic voices.
15. Consideration should be given to the appointment of a high profile patron to improve the visibility of the Centre and the organisation's profile amongst Australian women. This should be part of a comprehensive marketing and communication strategy.

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Appendix 1 National Centre for Gynaecological Cancers Project List

Objective 1: Improve information and supportive care for women with gynaecological cancers, their carers and families				
Project 1 Development and implementation of resources for consumers and health professionals	Project 2 National Centre for Gynaecological Cancers communications	Project 3 Building Cancer Support Networks	Project 4 Consumer Fellowships	
Objective 2: Support the workforce to deliver coordinated quality gynaecological cancer care				
Project 5 Clinical Research Fellowships	Project 6a Supporting the gynaecological cancers workforce: Review of Gynaecological Workforce	Project 6b Supporting the gynaecological cancers workforce: Development of the Gynaecological Cancers Service Delivery and Resource Framework	Project 6c Supporting the gynaecological cancers workforce: Support Coordination and Evaluation Hub	Project 6d Supporting the gynaecological cancers workforce: Jurisdictional projects (Development and implementation Gynaecological Cancers SD and RF)
Project 7a Development and implementation of professional development package for health professionals		Project 7b Psycho-sexual care module		
Objective 3: Build the evidence base for control of gynaecological cancers, including through research and clinical trials				
Project 8a Analysing patterns of referral for women with gynaecological cancers Development of survey instruments		Project 8b Analysing patterns of referral for women with gynaecological cancers Referral survey of GPs and Gynaecologists		
Project 9 Development and implementation of clinical practice guidelines for the management of women with endometrial cancers		Project 10 Priority-driven Cancer Collaborative Research Scheme		
Project 11a Development and implementation of minimum data sets for ovarian, cervical and endometrial cancers Development of the MDS		Project 11b Development and implementation of minimum data sets for ovarian, cervical and endometrial cancers Pilot testing; surgical synoptic reporting		
Objective 4: Build collaborative partnerships to improve outcomes for people affected by gynaecological cancers				
Project 12 National Centre for Gynaecological Cancers Advisory Group				

Evaluation of the National Centre for Gynaecological Cancers

Appendix 2 National Centre for Gynaecological Cancers – Stakeholder Survey Analysis

Introduction

This report describes a survey that was conducted to evaluate the experiences and views of key stakeholders involved with the National Centre for Gynaecological Cancers (NCGC). Of particular interest are the associations various stakeholders have with the NCGC and their opinions in regard to the overall effectiveness of the NCGC and its progress in addressing its objectives.

For this data collection, the stakeholders come from a diverse range of groups that influence the work of the NCGC and can be broadly classified as follows: Advisory Group members, NCGC personnel, Cancer Australia Executive, Project Leads (contracted by the NCGC), representatives from other jurisdictions and representatives of professional and/or consumer associations.

Survey Implementation

This survey was administered using Survey Monkey, an online application. Responses were entered throughout April and May 2010. The potential respondent pool of 61 stakeholders was emailed an introductory message including a participant information sheet and consent form. Customised emails were sent as necessary, to improve the response rate.

Response Rate

In total, 49 of the 61 (80.3%) stakeholders who received the survey attempted to complete it. The data were then assessed for their quality, usability and consistency to ensure a robust analysis could be performed. Following this, it was found that four out of the 49 respondents did not consent to participate and five consented but answered few or none of the questions. This left a total of 40 (65.6%) viable surveys which were used in the final analysis.

The 40 viable respondents included 27.5% who are currently involved in direct clinical service provision, leaving 72.5% who are not. A respondent classified as '*not being currently involved in direct clinical service provision*' does not equate with non involvement in relevant cancer control areas. There is a reasonably even mix of respondents (52.5%) who have a direct association with the NCGC and/or Cancer Australia for example, through membership of an Advisory Group/Strategic Forum, employment within Cancer Australia etc. The remaining 47.5%, whilst not directly associated with the NCGC in this same way, have had occasion to work/collaborate with the organisation over a sustained period. Furthermore, of these 40 respondents, 23 indicated at this time, their willingness to participate in an upcoming telephone interview.

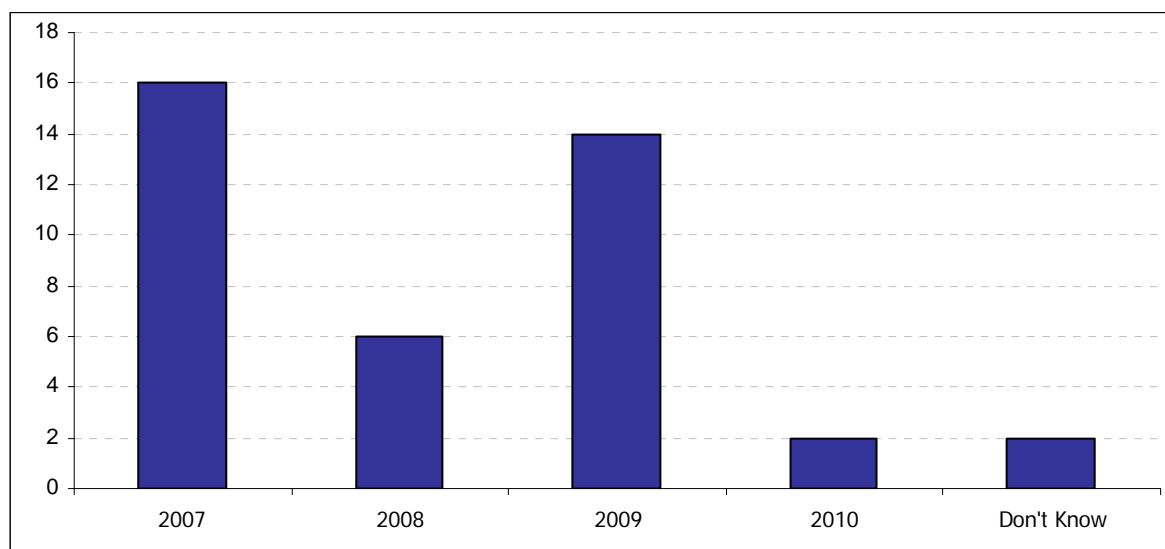
Table 4 Frequency of response types

Viable responses	40
Did not consent	4
Insufficient survey completion	5
No reply	12
Total Surveys Issued	61

Associations and Contributions to the NCGC

Figure 7 depicts the distribution of the timing in which respondents began their involvement with the NCGC. Most noticeably, there are a relatively large number of involvements beginning in 2007 and 2009. This appears to be logical as the Advisory Group was formed in 2007 and the organisation received an injection of new funds in 2008/2009 which led to new projects and working groups.

Figure 7 *Year in which involvement began with the NCGC*



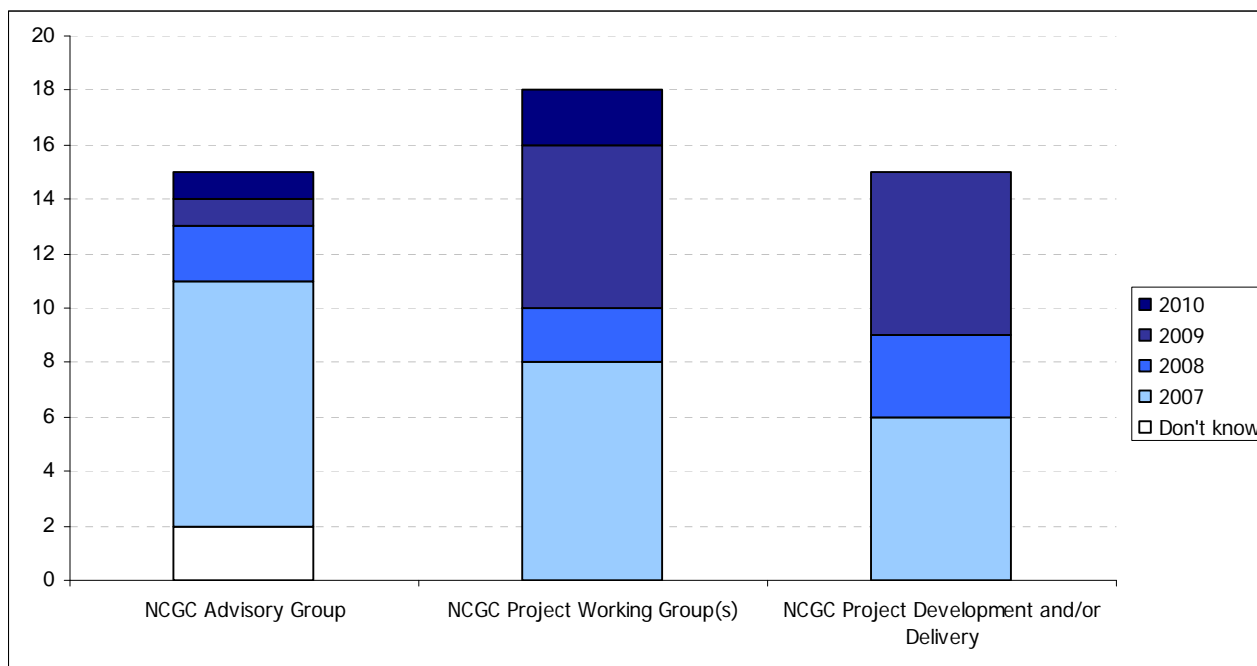
It can be seen from Figure 8 that the majority of respondents associated with the NCGC Advisory Group began their involvement in 2007. Across all three key NCGC activity groups, 2008 was a year where fewer respondents began their involvement.

The primary avenues for involvement with the NCGC are through membership of the Advisory Group, membership of a project related Working Group and/or through another aspect of project development and delivery. For example, several professional and consumer organisations may provide project advice but not participate on the Working Group. External experts engaged to support project development and delivery would also fit within this category.

The majority of survey respondents have an association with the projects of the NCGC, with 18 respondents involved in one or more Project Working Group(s) and 15 involved in other aspects of project development and/or delivery.

There were 15 respondents indicating involvement with the NCGC Advisory Group. The data in Figure 8 indicate that there have been relatively few new additions to the Advisory Group since 2007. This shows that there has been reasonably constant representation within the Advisory Group. Comparatively, the project-related activities show a larger turnover in involvements, which is not surprising given the time limited nature of the projects.

Figure 8 Respondents involved in NCGC activities by year involvement began



The Centre supports a diverse range of working groups as shown in Figure 9. The working groups with the highest participation amongst survey respondents include: the ‘Gynaecological workforce project’; ‘Development of clinical guidance material’ project; ‘Development of consumer information resources’ initiative and the ‘Psycho-sexual project’.

Figure 9 NCGC Project working groups respondents contributed towards

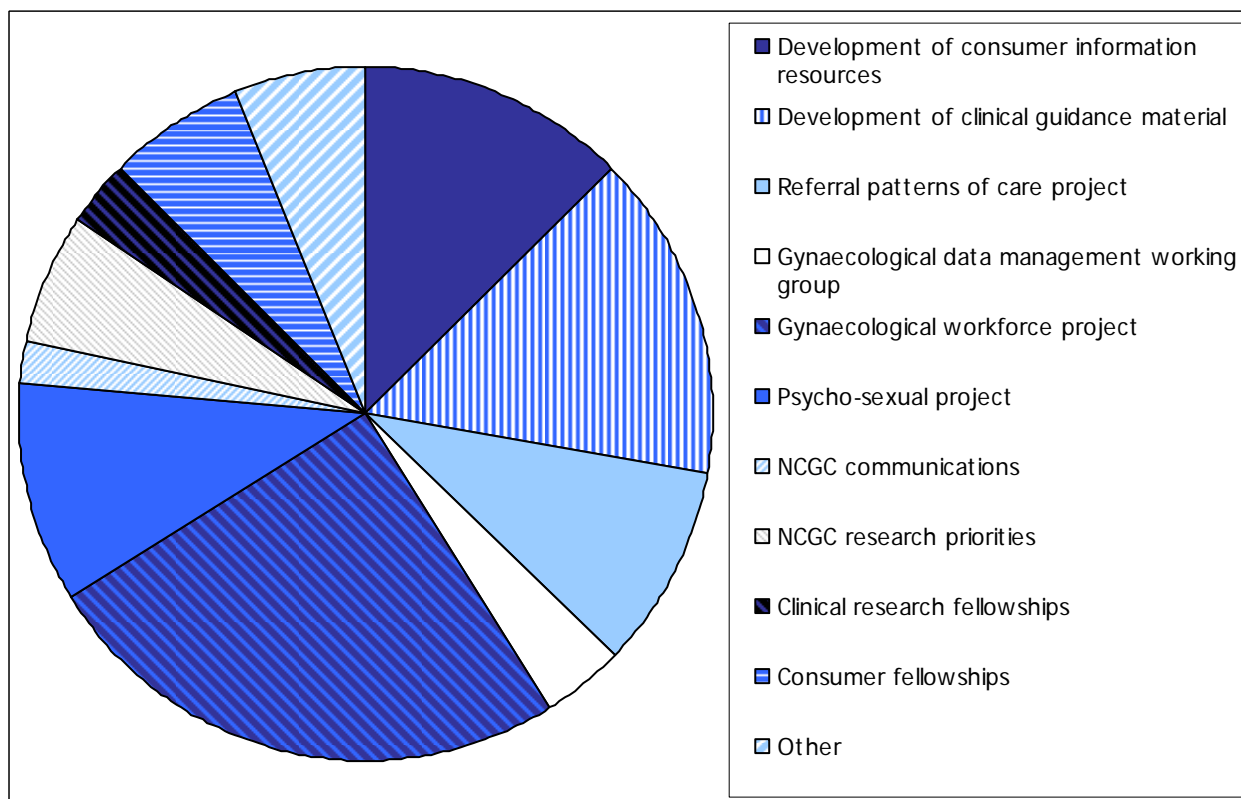


Figure 10 shows the level in which respondents believe they can contribute towards the three key activity groups of the NCGC. Overall, all three of the activities have a similar looking distribution. The majority of respondents either agreed or strongly agreed that they could contribute effectively towards these activities. In regard to contributions towards projects of the NCGC, almost 25% strongly agreed that they could contribute effectively, while approximately 15% strongly agreed for the other activities. For all three activities the proportion of respondents disagreeing about contributing effectively was around 10% and no one strongly disagreed.

Using Kendall's tau correlation coefficient (a statistic used to measure associations between paired ordinal variables), an apparent association between these three questions was revealed. This means that increases in agreement in one of the questions will likely be coupled with an increase in agreement for the other two questions. This shows that there is consistency amongst the three activities in terms of how effectively the respondents believe they can contribute.

In the open-ended response section there was both positive and negative feedback. The positive feedback came from consumers who feel their contributions are welcomed and uninhibited by the NCGC. However, the negative feedback indicates that the activities in the NCGC may be overridden by bureaucratic powers imposed from higher levels of government. This leads to some individuals feeling that their contribution is at times overlooked.

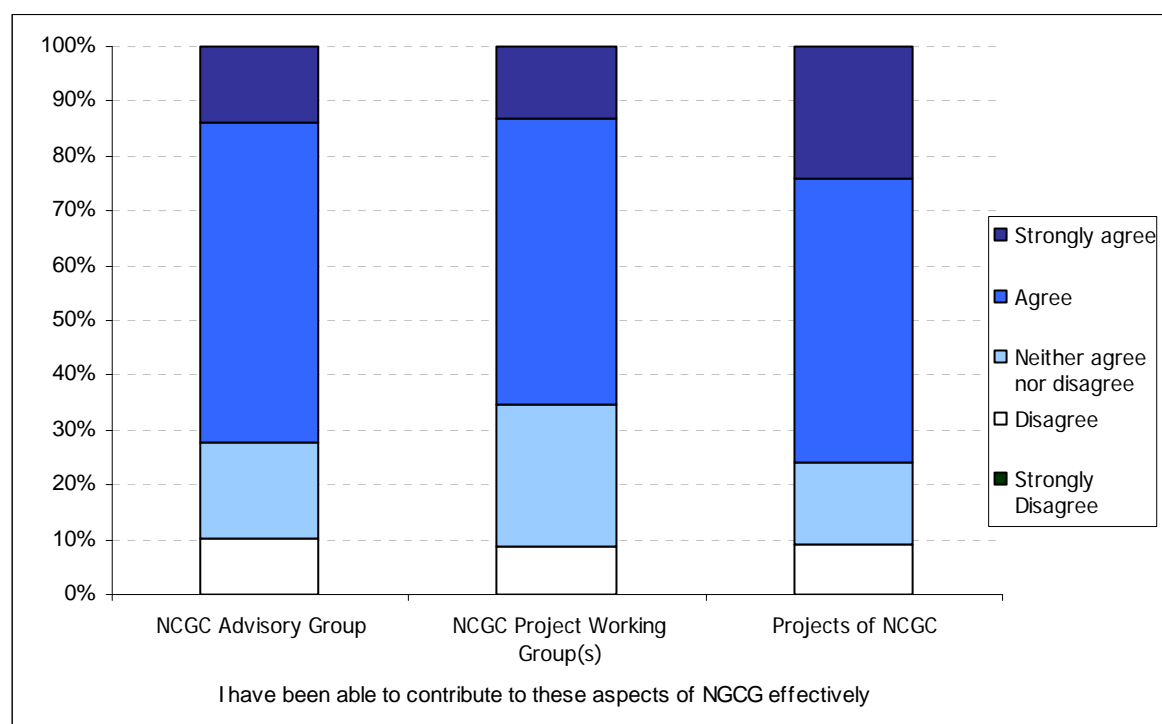
Comments that especially highlight these issues are as follows:

“The bureaucracy around the Projects and Working Groups is cumbersome, though I recognise that this is 'imposed' from above and hard to reduce. It does seem to add inordinate time/costs to everything...”

“... All projects are decided upon and we are then left to rubber stamp them.”

“It seems to me that the NCGC 'bureaucracy' has at some times interfered with the direction that projects might take, possibly on a 'cost saving' approach.”

Figure 10 Aspects of NCGC respondents contributed towards

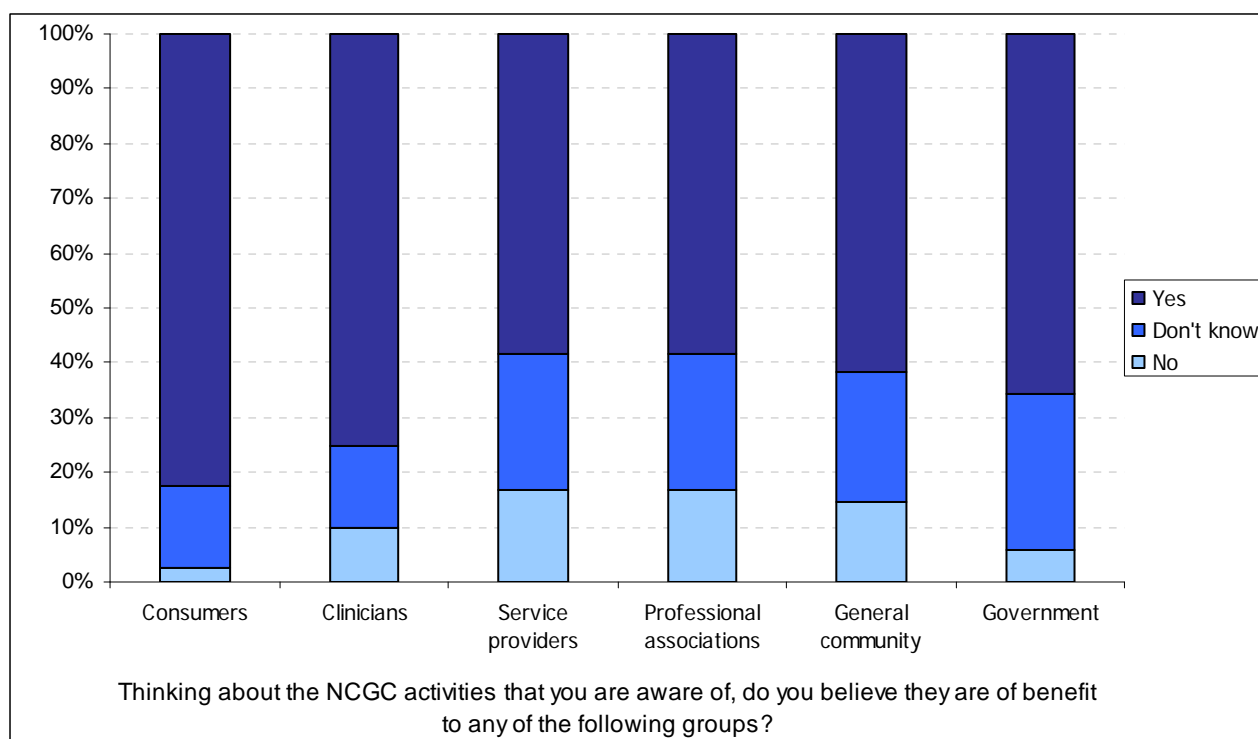


The views on whether stakeholders believe that the activities they belong to actually benefit certain groups is shown in Figure 11.

There is a very strong indication that respondents believe consumers benefit from the activities of the NCGC, with only one of 40 respondents saying otherwise. The same can be said of the perception that clinicians would benefit. The other four groups still show a majority of respondents suggesting that NCGC activities would benefit them, but not to the same extent as consumers and clinicians. There are slightly more ‘Don’t know’ responses for these four groups indicating there is less certainty in the perceived benefits to service providers, professional associations, the general community and the government. This could be a reflection of the level of involvement of respondents with the NCGC or may be related to the fact that benefits are hard to assess without more concrete information provided.

Another factor for consideration is whether the NCGC is the sole contributor to improving benefit to these groups. This makes it difficult to attribute specific benefit to the NCGC. The overall impression however is that NCGC activities are of some benefit to a diverse selection of groups, especially consumers and clinicians.

Figure 11 *NCGC activities and their benefits to stakeholder groups*



6 Effectiveness of the NCGC

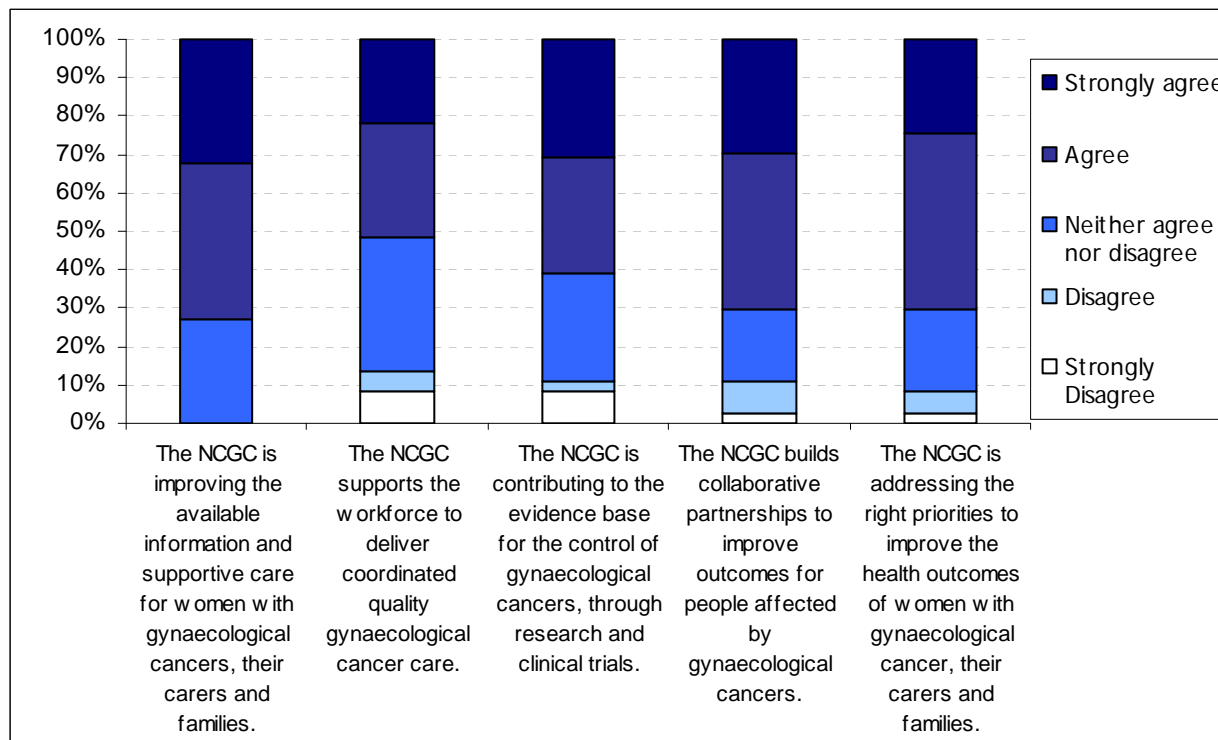
Figure 12 below displays the opinions of stakeholders to five statements concerning the NCGC. These statements are based on the key objectives of the NCGC and aim to illustrate stakeholder views as to the effectiveness of the NCGC in addressing these objectives.

The most notable feature is in the first bar corresponding to the improvement of available information and supportive care for women with gynaecological cancers, their carers and families (i.e. consumers). Not one respondent disagrees or strongly disagrees with this statement. This supports the findings in Figure 11 which also shows positive results in relation to the perception of the way the NCGC treats consumers.

In the other four statements in Figure 12 there is a portion of respondents who expressed some form of disagreement. The statement exhibiting most disagreement (and neutrality) relates to the NCGC supporting the workforce.

The remaining responses are reasonably similar to each other with a large majority of agreement amongst the respondents. It should be noted that the statement referring to how the NCGC contributes to the evidence base for the control of gynaecological cancers, through research and clinical trials has three respondents that strongly disagreed.

Figure 12 Effectiveness of tasks undertaken by the NCGC



In total, 86% of respondents believe the NCGC does do things well, leaving 14% who do not believe there are things done well. The main things that the respondents believed the NCGC is doing well include:

- effectively building and improving collaborations between organisations, stakeholders and agencies
- engaging consumers and providing them with support, information and involvement
- networking the clinicians and researchers in the area.

With respect to whether there are things the NCGC should do better, 58% believe there are and only 8% believe there are not, while the remainder are unsure. Unsurprisingly, all respondents who believe there are no things that the NCGC does well also believe there are things that they should do better.

Some specific improvements suggested were:

- communicate more effectively with stakeholders
- organise and maximise use of resources
- maintain key focus and aims
- raise the profile of the NCGC
- gain a much stronger knowledge of the field.

In general it appears as though there are things that the NCGC does well, but there are still some further things the NCGC can improve on.

Figure 13 Overall NCGC performance

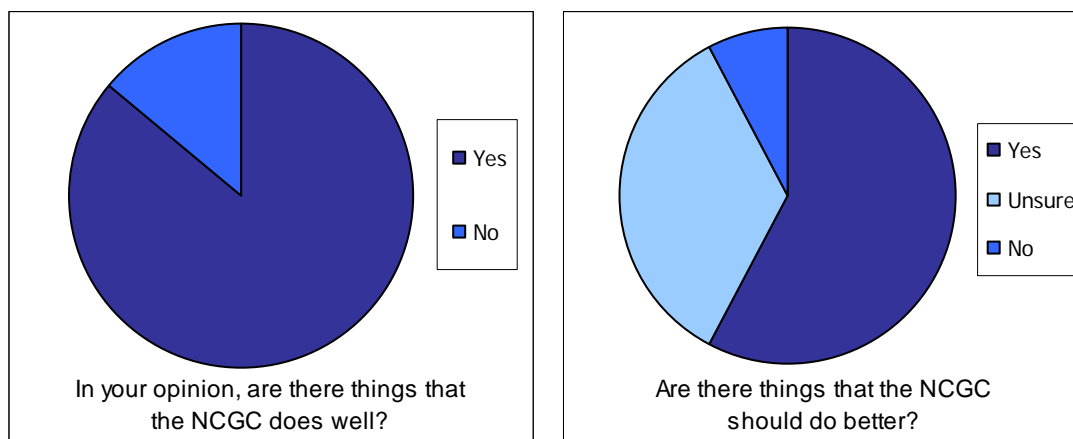
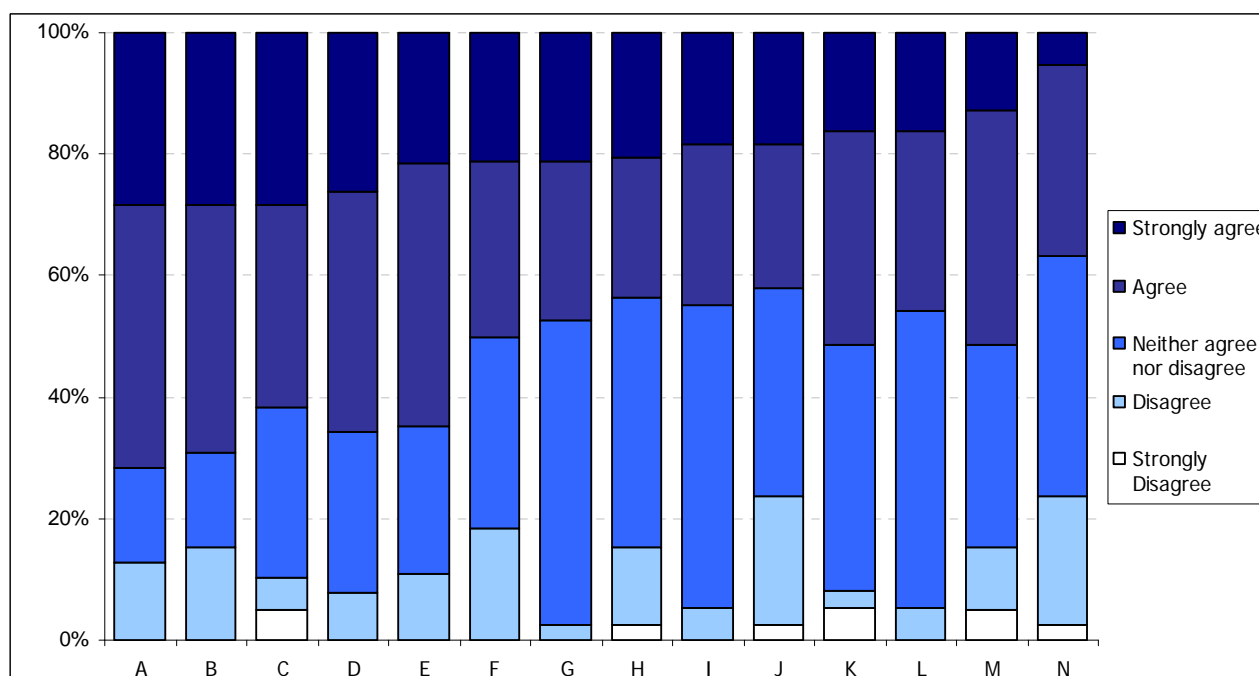


Figure 14 Effectiveness of the role of the NCGC



- A I am satisfied with my involvement with the NCGC.
- B The NCGC consults well with stakeholders.
- C The NCGC has established effective ways to communicate with me.
- D The NCGC effectively establishes collaborative partnerships.
- E The NCGC sets the right strategic priorities.
- F The NCGC is making a positive impact in the cancer control sector.
- G The NCGC utilises its financial resources wisely.
- H The projects delivered by the NCGC provide important lessons for others in how to do things better.
- I The NCGC manages grants effectively.
- J The NCGC selects the right contractors/service providers to implement projects.
- K The NCGC builds the capacity of the cancer control sector.
- L The NCGC monitors outputs effectively.
- M The NCGC adequately disseminates information about the work of the Centre.
- N The NCGC is trying to address too many demands.

The overall impression conveyed in Figure 14 is mostly of agreement or neutrality of the provided statements. Statements J and N had the largest proportion of disagreement (including strong disagreement) with a proportion of 23.7% for both items. This means that respondents feel that the NCGC has difficulty selecting the right contractors/service providers to implement projects.

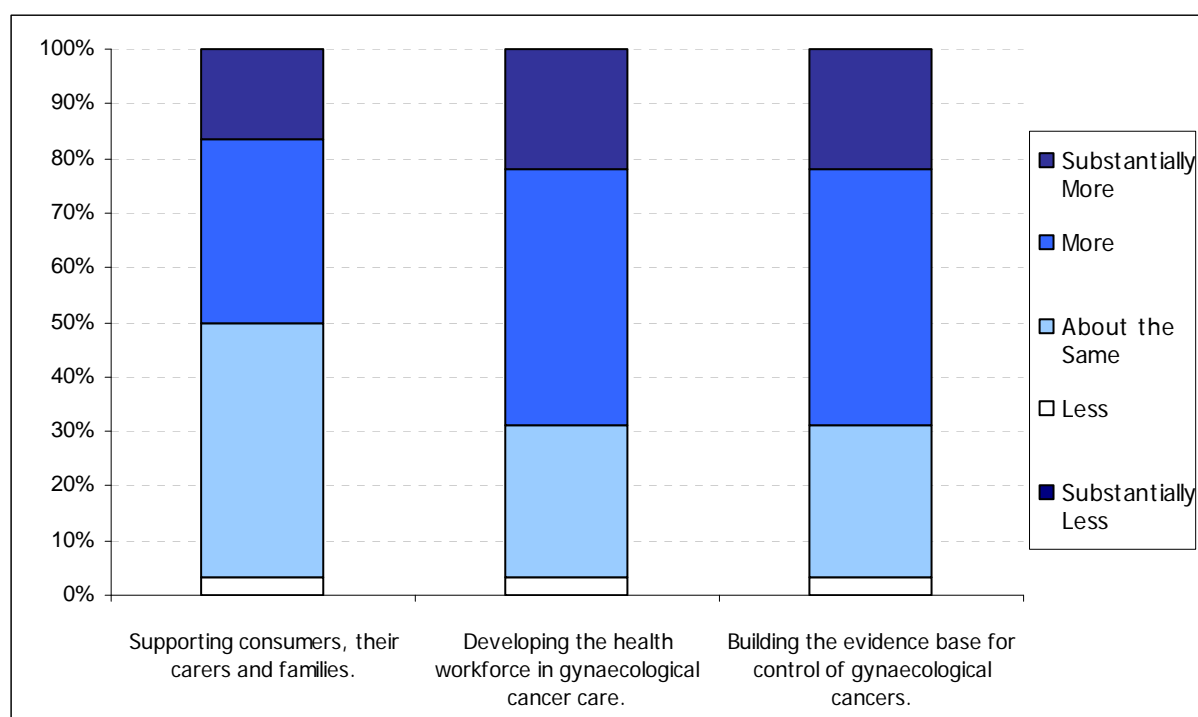
Statement N ‘The NCGC is trying to address too many demands’ also has the lowest proportion of agreement. This is to be expected as Statement N is the only negative statement out of the fourteen. This would suggest that there is not strong belief that the NCGC is trying to address too many demands.

The statements with highest level of agreement come from A and B suggesting that the majority of respondents believe the NCGC is consulting well with stakeholders and are satisfied with their own involvement. All the other statements also have a substantial amount of strongly agrees and agrees, but to a slightly lesser extent.

There are several noteworthy associations observed between responses to certain statements in this part of the survey. Firstly, there is a very strong association between responses to statements F and K which indicates that building the capacity of the cancer control sector is also making a positive impact. Responses to Statement K also have a high correlation with the questions shown in Figure 12 relating to views about the effectiveness of the NCGC in relation to tasks undertaken to support organisational objectives. These questions address specific ways of building the capacity of the cancer control sector. Another strong association appears between statements A and C which would suggest the NCGC communicating effectively with the respondents is related to a higher satisfaction with their own involvement.

Figure 15 displays the views on resource allocations and whether there should be an increase or decrease in different areas. The distribution of responses for resource allocation in ‘Developing the health workforce in gynaecological cancer care’ and ‘Building the evidence base for control of gynaecological cancers’ were exactly the same. Almost 70% of respondents believe more or substantially more resources should go into these areas, while only one respondent (making up 3.1%) believes fewer resources should be allocated.

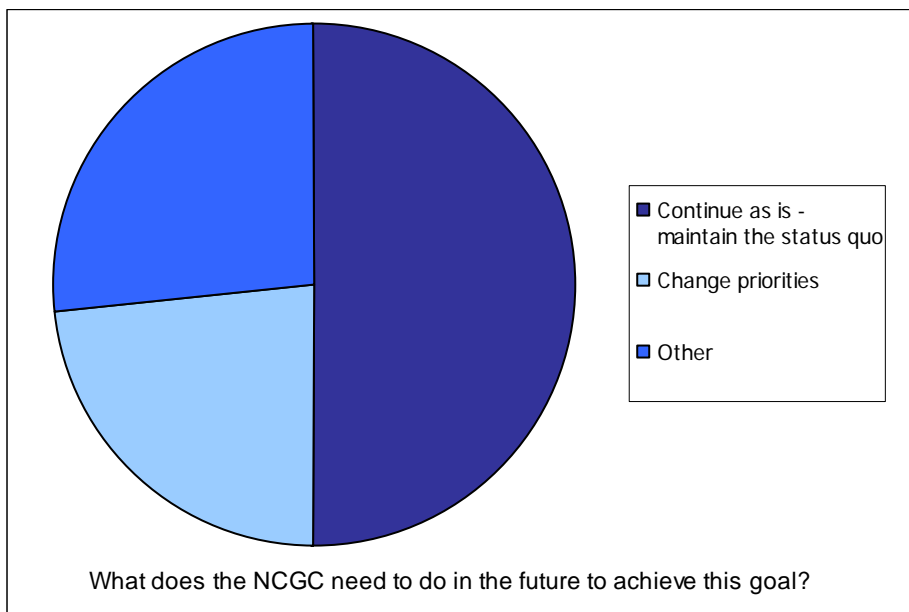
Figure 15 NCGC resource allocations



In regard to resource allocation in 'Supporting consumers, their carers and families', 50% believe there should be more and almost 50% believe it should remain the same. This reveals that the respondents are more satisfied with resource allocation in this area.

Exactly half of respondents believe that continuing as is will lead to the NCGC achieving its goal of improving the health outcomes of women with gynaecological cancer, their carers and families. This left 23.3% who think that a change in priorities is necessary.

Figure 16 *Actions in achieving the goal of the NCGC*



Some of these suggestions include:

- increase preventable strategies
- enhance awareness about gynaecological cancers
- increase collaborations to help improve such things as health outcomes and innovative models of care and
- unite groups across States and Territories.

7 Summary

Overall, the respondents believe that the NCGC is performing well. It is addressing its key objectives, fulfilling its role and implementing its activities effectively. Despite only being recently established, the general feedback strongly indicates that the perception of respondents is that the NCGC is bringing about a positive impact for women with gynaecological cancer, their carers and families.

This is supported by such comments as:

"I think that the establishment and continuing development of the NCGC has been a very positive step towards informing and improving care for women."

The key messages from this survey are summarised below:

- Respondents are most positive about the way the NCGC engages its consumers. The majority of respondents believe that consumers are benefiting from the work the NCGC does

through their support and involvement with them. This appropriately aligns with the Senate Inquiry that led to the establishment of the Centre.

- The NCGC's ability to engage with all stakeholders and groups is effective and provides individuals and organisations purposeful ways to contribute to the NCGC. This strong engagement has created effective collaborations which contributes to the work of the Centre.
- There is an indication that although the collaborations are effective, the communication between certain groups can be improved. It is important to have cohesion between stakeholder groups as this supports achievement of the objectives of the Centre. There is a view that more work is needed to engage clinicians in the work of the Centre and develop workforce capacity. This is a pivotal relationship in terms of the sustainability of the NCGC.
- There are beliefs that as a national organisation the Centre requires more emphasis on inter-jurisdictional projects across Australia.
- An area in specific need of improvement is the dissemination of information and creation of awareness about the NCGC. There are opinions that raising the profile is a very necessary component in the successful advancement of the Centre. As a recently established Centre it is understandable that the NCGC does not have a high profile, although this is something that can be built on in the future.
- There is a high level of personal satisfaction amongst those involved with the NCGC which is likely to be attributed to the high level of involvement they feel with the Centre.
- The greatest negativity in relation to the effectiveness of the NCGC comes from a belief that the operations of the NCGC are impeded by bureaucracy. These references to bureaucracy are about the 'machinery of government' as opposed to the day to day operations of the Centre. This has led to feelings of frustration amongst some stakeholders who feel the progress of the Centre could be undermined by bureaucrats who do not have expertise in the gynaecological cancer field. This is very clearly not directed at staff of the NCGC but at higher levels of government. Some stakeholders felt this trivialises their contribution.
- There is recognition and frustration at the limited resources afforded to the NCGC and that authority for expenditure ultimately rests with government.
- In many instances, respondents commented on the short lifespan of the NCGC and how this by necessity, limits the contribution of the Centre to date.

In conclusion, whilst the survey identifies some areas for improvement for the NCGC, there are many positive and encouraging comments about the Centre and its activities. In the view of respondents to this survey, the NCGC appears to be functioning effectively and progressing towards its future goals.

Appendix 3 Key Performance Indicators

Key Performance Indicators (KPIs) should be aligned with organisational objectives and/or the 'required changes' of the NCGC program logic. They will measure project delivery and organisational impact. They should be specific, measurable, realistic and time-framed.

Potential KPIs gathered during the consultation process are listed below. These require further discussion and review.

Consumers

- number of information resources published for women with gynaecological cancers, (with a specification of one within 2010-11)
- number of information resources published for women that address genetic factors in gynaecological cancers
- trends in consumer awareness of specific clinical trials
- increased uptake of clinical trials by women with gynaecological cancers
- trends in consumer satisfaction and participation within the NCGC
- periodic assessment of women's experience of gynaecological cancer care. (The development of the NGCSDRF used surveys for women and their carers to rate their experience of care and comment on areas of improvement that they saw and establish a baseline).

Service Providers

- trends in health professionals awareness and uptake of training programs and resources (utilisation of on-line training modules, award of Continuing Professional Development –CPD-points)
- increased dissemination and adoption of clinical guidelines (number of clinical guidelines distributed and number of clinical guidelines adopted)
- types of clinical practice changes generated by clinical guidelines (this may be measured by a practice survey)
- trends in referral practices (e.g. time to referral)
- increased numbers of 'co-operative groups' for clinical trials relevant to gynaecological cancers
- proportion of Australian gynaecology-oncologists that participate in activities of the NCGC.

System

- % of projects that have a demonstrable link to the 'required changes' of the NCGC program logic
- % of States and Territories with specialist gynaecological services participating in at least one gynaecological cancer project, (with a 2010-11 Budget Target of 100%)
- number of instances of research translation into policy and practice. (e.g. change in medical curricula through adoption of clinical guidelines)
- number of women's organisations with formal partnerships with the NCGC (per annum or trends over time)
- number of media releases issued by the NCGC per annum

Several of the elements within the NGCSDRF could lend themselves towards becoming standards or indicators that could be developed and evaluated - potentially these will be incorporated by Siggins-Miller in their evaluation framework for the NGCSDRF.

Appendix 4 Evaluation Tools

1. NHS Sustainability Tool

To try and gain some quantification of the likely sustainability of the improvements made by the NCGC over time, it may be useful to review the sustainability tool developed in the National Health Service in the UK by Lynne Maher from the NHS Institute for Innovation and Improvement and two researchers from the University of Wisconsin (Maher, Gustafson et al. 2006). It is designed to be used prospectively and has been applied in hospital settings and can be used to:

- predict the likelihood of sustainability
- self-assess against a number of key criterion for sustaining change
- recognise and understand key barriers for sustainability, relating to their specific local context
- identify strengths in sustaining improvement
- plan for sustainability of improvement efforts
- monitor progress over time.

The tool uses a scoring system based on 10 factors (each with four options for scoring) grouped in three categories. It may be possible to modify this tool to better meet the needs of NCGC partnerships.

NHS sustainability tool – categories and factors

Category	Factor
Process	Benefits beyond helping patients Credibility of the benefits Adaptability of improved process Effectiveness of the system to monitor progress
Staff	Staff involvement and training to sustain the process Staff attitudes toward sustaining the change Senior leadership engagement Clinician leadership engagement
Organisation	Fit with the organisation's strategic aims and culture Infrastructure for sustainability

The highest possible total score for the NHS Sustainability Model is 101. According to the authors of the model preliminary evidence suggests that a score of 55 or higher offers reasons for optimism that sustainability will be achieved

Maher, L., D. H. Gustafson, et al. (2006). "NHS Sustainability Model." from http://www.institute.nhs.uk/index.php?option=com_joomcart&Itemid=194&main_page=document_product_info&cPath=67&products_id=290.

2. Partnership Tool

The development of partnerships can be a critical factor in the successful implementation of projects. It takes time for newly established partnerships to become fully productive, which makes the process of evaluating partnerships somewhat complex (Pope and Lewis, 2008). Interviews with 120 people involved in ten community development partnerships in Victoria investigated the structure of networks that had been developed and the value placed on them by participants in the partnerships. Analysis of these networks highlighted five characteristics of effective partnerships, namely: a good broker/facilitator to build relationships; the right decision makers at the table with a commitment to contribute; a clear purpose; good process; and ongoing monitoring (Pope and

Lewis, 2008). The importance of these factors was confirmed by a recent review of the literature on partnership building in ageing policy, in which Warburton and colleagues (2008) identified six factors that contribute to the success of collaboration. These are:

1. context (a history or culture of collaboration; favourable socio-political climate; supportive financial climate)
2. characteristics of partners (diversity of membership; grass-roots involvement; skills such as flexibility, negotiation and ability to work across professional boundaries; mutual inter-dependence and equal power)
3. procedures (frequent, open and culturally-sensitive communication; joint decision making through deliberation)
4. structures (formalised and clearly defined, but not bureaucratic; a learning environment; coordination and monitoring role of convenor or leader)
5. purpose (concrete attainable goals, different from yet consistent with those of the participating organisations; strategic importance; innovation)
6. resources (funding; a skilled convenor; willingness of members to exercise leadership skills; local knowledge and specialist expertise)

In Australia, a recommended partnerships analysis tool is the *Vic Health Partnerships Analysis Tool* (McLeod, 2004) as it lends itself to partnership development and evaluation. A recent paper by Sunderland, et al. (2009) uses the *Vic Health Partnerships Analysis Tool* to evaluate partnerships and found low uptake (47%) of the self-evaluation form across 17 partner primary health care organisations. The authors suggest that the organisations needed more time and assistance in completing the instrument; and a better understanding that the instrument provides a useful opportunity to dialogue and reflect on partnership development. In addition, this paper highlights the benefits of facilitated use of the *Vic Health Partnerships Analysis Tool*; using agreed terminology and tailored to the local situation / context.

It may be possible that NCGC project final reports provide information on the success or otherwise of the partnerships established, the difficulties encountered, and the benefits that flowed from effective partnerships.

The Partnerships Analysis Tool – Vic Health

<http://www.vichealth.vic.gov.au/en/Resource-Centre/Publications-and-Resources/VicHealth-General-Publications/Partnerships-Analysis-Tool.aspx>

Pope J and Lewis JM (2008) *Improving partnership governance: using a network approach to evaluate partnerships in Victoria*. Australian Journal of Public Administration, Vol. 67, No. 4, pp. 443-456.

Quinsey K, Williams K, Westera A and Morris D (2009) *Care Planning Sub-Program: findings from the national evaluation*. Centre for Health Service Development, University of Wollongong.

Sunderland N, Domalewski D, Kendall E, et al. (2009) *Which comes first: the partnership or the tool? Reflections on the effective use of partnership tools in local health partnerships*. Australian Journal of Primary Health. Vol. 15, pp. 303-311.

Warburton J, Everingham J, Cuthill M and Bartlett H (2008) *Achieving effective collaborations to help communities age well*. Australian Journal of Public Administration, Vol. 67, No. 4, pp. 470-482.

McLeod J (2004) *The Partnerships Analysis Tool: For partners in health promotion*. VicHealth (Victorian Health Promotion Foundation), Melbourne.

3. Dissemination Log

Dissemination logs provide a simple tool to capture dissemination activities carried out by projects across an agreed time period. Project officers are asked to classify their dissemination activities by purpose, for example, to support capacity building and/or sustainability. This might include project presentations to key stakeholder organisations. A sample log is included in Table 5 below which shows the quantitative data that can be captured from projects.

Table 5 *Types of dissemination activities - October 2007 to March 2009*

Dissemination activity	Total activities	Percent of activities	Range across projects
Presentation or talk to staff at cancer control agency	246	50.0	0-75
Presentation or talk to staff from more than one cancer control agency	29	6.0	0-9
Presentation or talk to staff from one or more services or agencies	96	19.4	0-46
Story in the local newspaper	1	0.2	0-1
Story in a local magazine or newsletter (e.g. GP news, Gynae newsletter)	8	1.6	0-4
Story in a professional or industry magazine or newsletter	3	0.6	0-1
Story on radio	1	0.2	0-1
Story on television	-	-	-
Presentation or poster at a local conference	1	0.2	0-1
Presentation or poster at a State/Territory conference	1	0.2	0-1
Presentation or poster at a national conference	4	0.8	0-2
Peer-reviewed journal article	-	-	-
Information provided on a website	5	1.0	0-1
Email communication to groups/lists	13	2.6	0-5
Brochures, leaflets or posters in health and community settings	6	1.2	0-2
Project newsletter	8	1.6	0-3
Other	70	14.2	0-35
Total	492	100.0	-

EBPRAC Evaluation Team (2008). *Encouraging Best Practice in Residential Aged Care: Second Annual Evaluation Progress Report*. Centre for Health Service Development, University of Wollongong.

4. Evaluation Framework Checklist

Issue		Is this a goal of the activity being evaluated?		To be included in the scope of the evaluation?	
Levels to be evaluated					
Level 1	The impact on, and outcomes for, consumers (patients, families, carers, friends, communities)	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Level 2	The impact on, and outcomes for, providers (professionals, volunteers, organisations)	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Level 3	The impact on, and outcomes for, the care delivery system (structures and processes, networks, relationships)	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Questions to be answered in the evaluation					
Service or project delivery The evaluation task is to describe ' <i>what did you do?</i> ' at each level				Yes <input type="checkbox"/> No <input type="checkbox"/>	
Service or project impact The evaluation task is to evaluate ' <i>how did it go?</i> ' at each level				Yes <input type="checkbox"/> No <input type="checkbox"/>	
Service or project sustainability Is the goal to retain the service or project on an ongoing basis? If so, the evaluation task is to evaluate ' <i>can you keep going?</i> ' at each level		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Service or project capacity building Does the service or project aim to develop improved capacity to meet the needs of women with gynaecological cancers, their carers and families? If so, the evaluation task is to evaluate ' <i>what has been learnt?</i> ' at each level		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Service or project generalisability Does the service or project aim to have an impact that is broader than the immediate catchment area or target group? If so, the evaluation task is to evaluate ' <i>are your lessons useful for someone else?</i> ' at each level		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Dissemination Does the service or project aim to communicate with, or share its lessons and experiences, with consumers, providers or services? If so, the evaluation task is to evaluate ' <i>who did you tell?</i> ' at each level		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Adapted from the *Palliative Care Evaluation Framework Checklist* in: Eagar K, Cranny C and Fildes D. **Evaluation and palliative care: a guide to the evaluation of the palliative care services and programs**. Commonwealth of Australia, 2004.