National Gynaecological Cancers
Service Delivery and Resource Framework
List of figures

Figure 1: National Gynaecological Cancers Service Delivery and Resource Framework 7
Figure 2: The tiered approach to service levels for providing care for women with suspected or confirmed gynaecological cancer 21
Figure 3: Linking service delivery elements, service models and outcomes 27
Figure 4: The tiered approach to providing supportive care 49

List of tables

Table 1: Current and projected incidence of gynaecological cancer by jurisdiction 8
Table 2: Overview of the eight service delivery elements 18
Table 3: Key features of the three different gynaecological cancer service models 25
Table 4: Gynaecology oncology workforce estimates 33
Table 5: Estimated number of gynaecological oncologists by jurisdiction by 2015 34
Table 6: Estimated numbers of women currently requiring external radiotherapy or brachytherapy based on optimal utilisation rates 38
Table 7: Ratios of medical oncologists to population by jurisdiction 41
Table 8: Suggested competency levels for nurses caring for women with gynaecological cancers in different service contexts 47
Table 9: Supportive care resources within Australian specialist centres 50
Table 10: The specific skills and requirements for specialist psychosocial supportive care providers working within different service contexts 53
Table 11: Specific skills for Aboriginal health and community workers working in different service contexts 60
Table H.1 Summary of content of the service mapping tool 101
Table H.2 Referral providers and catchments 102
Table H.3 Service volume and discipline-specific resources 103
Table H.4 Reported frequency of attendance at multidisciplinary meetings across services 104
Table H.5 Number of services reporting frequency of multidisciplinary activities and supportive care practices 105

List of appendixes

Appendix A: Glossary 64
Appendix B: Project method for developing the National Framework 69
Appendix C: Project advisory mechanisms 70
Appendix D: Consultation and workshop participants 72
Appendix E: Detailed summary of women’s needs 79
Appendix F: The eight service delivery elements in detail 82
Appendix G: Advantages and disadvantages of different service models 99
Appendix H: Summary of service mapping findings 101

Abbreviations

AIHW Australian Institute of Health and Welfare
ANMC Australian Nursing and Midwifery Council
ANZGOG Australian New Zealand Gynaecological Oncology Group
ASCOP Australian Society for Colposcopy and Cervical Pathology
ASGO Australian Society of Gynaecologic Oncologists
CALD Culturally and linguistically diverse [backgrounds]
CanNET Cancer Service Networks National Program
EdCaN National Cancer Nursing Education Project
EFT Equivalent full-time
GP General practitioner
GTD Gestational trophoblastic disease
HPV Human papilloma virus
IGCS International Gynaecologic Cancer Society
ISGP International Society of Gynaecological Pathologists
MBS Medicare Benefits Schedule
MOGA Medical Oncology Group of Australia
NBICC National Breast and Ovarian Cancer Centre
NSDC National Centre for Gynaecological Cancers
NHMRC National Health and Medical Research Council
PEPA Program of Experience in the Palliative Approach
RACP Royal Australian College of General Practitioners
RACP Royal Australian College of Physicians
RANZCOG Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RANZCR Royal Australian and New Zealand College of Radiologists
RCPA Royal College of Pathologists of Australasia
TRG Trans-Tasman Radiation Oncology Group

Preface

The National Gynaecological Cancers Service Delivery and Resource Framework (the ‘National Framework’) is a project of Cancer Australia’s National Centre for Gynaecological Cancers – an Australian Government initiative to improve outcomes for women affected by gynaecological cancers, their families and carers. It was undertaken in partnership with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

The National Framework considers the challenges facing the current and future gynaecological cancer workforce with a key focus on ensuring the best use of available resources. It has been guided by the needs of women with gynaecological cancers and is the result of close collaboration with a range of key stakeholders from around the country with diverse views and perspectives. The development of the National Framework was guided and supported by a Project Working Group and a Consumer Reference Group.

We hope that health professionals, the jurisdictions and relevant professional and Commonwealth bodies will work together to identify appropriate mechanisms to maximise the uptake of this National Framework, and use the framework to better inform gynaecological cancer health service and workforce planning and development.

For any queries or comments regarding this document, please contact Cancer Australia via www.canceraustralia.gov.au.

[Handwritten signatures]

Professor Sanchia Aranda Chair National Centre for Gynaecological Cancers Advisory Group
Dr Gerry Wain Chair Project Working Group

June 2011
Cancer Australia and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists would like to thank the following people and organisations for their valuable contribution towards this National Gynaecological Cancers Service Delivery and Resource Framework (the ‘National Framework’):

- Sheila Hirst (Sheila Hirst Consulting) who was commissioned to develop the National Framework in partnership with Alison Amos (ECHO – Extending the Capacity of Healthcare Organisations)
- the members of the Consumer Reference Group (Appendix C) who provided invaluable insights into the experiences of women with gynaecological cancers
- the Chair and members of the Project Working Group (Appendix C) who provided significant guidance throughout the development of the National Framework; and supporting staff of Cancer Australia
- individual members of the National Centre for Gynaecological Cancers Advisory Group and many other individuals who provided ongoing advice and information (Appendix C)
- staff of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- the following professional colleges who have supported the development of the National Framework in a variety of ways:
  - Medical Oncology Group of Australia (Royal Australasian College of Physicians)
  - Royal College of Pathologists of Australasia
  - Royal Australian College of General Practitioners
  - Royal Australian and New Zealand College of Radiologists
  - Royal College of Nursing, Australia

Cancer Australia, through its National Centre for Gynaecological Cancers (NCGC), in partnership with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), has developed the National Gynaecological Cancers Service Delivery and Resource Framework (the ‘National Framework’).

Developed with extensive stakeholder consultation, this framework provides a way forward for future service development to enhance access to optimal multidisciplinary care for all Australian women with or at risk of a gynaecological cancer.

The National Framework has been informed by a review of current and future service demand, women’s needs and evidence from the peer-reviewed literature and consultation findings. It aligns with current cancer reforms and broad health policy directions.

The framework addresses all parts of the pathway journey from prevention to palliation and is based on the best available evidence. Where high-level evidence is unavailable, the framework draws on expert opinion and consensus (Level IV evidence) to guide optimal care.

The framework has the following components:

- overarching goals and principles to guide gynaecological cancer services
- eight service delivery elements that must be met to ensure optimal care for women
- the organisational approaches and structures required to ensure the flexible and robust service models required to appropriately meet service demand
- identification of the workforce requirements (resources or skills) needed to ensure a skilled and supported multidisciplinary workforce.

Using the National Framework

This framework was developed for use by consumers, individual service providers, service units, service managers, professional bodies and key policy providers, often working in collaboration with each other. Specifically, it is recommended:

For consumers to:
- use the framework to develop an understanding of the best practice requirements of services to support women with a gynaecological cancer.

For individual service providers to:
- review professional practice and identify professional development needs.

For gynaecological cancer service units to:
- review current services against the eight service elements for a quality gynaecological cancer service to:
  - demonstrate current service strengths
  - identify opportunities and priorities for future service improvement
  - implement and evaluate strategies to address identified service gaps
- review workforce resources and skills and identify how any gaps can be best met within the service context; this includes addressing access to discipline-specific skills as well as general skills that transcend specialist disciplines, e.g. general supportive care and palliative care skills and skills to address psychosexual needs
- identify improved resources, training opportunities, systems and processes to strengthen services and practices over time.

For health service managers and service executives to:
- review and define the service requirements and workforce capabilities needed within the practice setting and service model to provide quality services for women with gynaecological cancers across the pathway of care
- examine and measure cancer service demand and other service demands (e.g. ‘non-cancer’ service demand) that are impacting on overall gynaecological cancer service delivery and its workforce
- implement strategies to address gaps in service requirements and workforce capabilities and those factors impacting on service delivery and the workforce
- maximise investment by identifying opportunities to align gynaecological cancer service delivery and workforce improvement strategies with the health service’s broader cancer or health service direction.

For professional colleges and related organisations to:
- review the gynaecological cancer workforce resource issues and/or skills as related to their professional discipline and develop strategies to address these. Strategies may be specific to gynaecological cancer workforce resources or skills or be part of general initiatives to address broader specialist (e.g. medical oncology or specialist palliative care) or generalist workforce issues
- develop additional guidance or educational resources required to support professional practice
- identify those aspects of service delivery that may influence professional practice but require further exploration (e.g. through research or clinical audit) and seek opportunities or partnerships to undertake this work
- encourage linkages between individual specialists and sub-specialists across agreed organisational networks to facilitate professional development and peer support.

For jurisdictions to:
- actively encourage all gynaecological cancer services to review their services against the eight service elements and identify and address areas for improvement
- work with key stakeholders, including clinicians, service executives and planners and consumers to consider, agree on and implement:
  - the future service configuration and service mix for the jurisdiction
  - the specific requirements for different services within the overall service configuration
  - the organisational arrangements or clinical networks required within their regions or jurisdictions to meet the population needs, and optimise communication and collaboration between all relevant services and service providers
- work with its workforce unit, its state or territory representatives of relevant professional colleges and individual stakeholders as appropriate to identify:
  - the specific current and future gynaecological cancer workforce requirements
  - opportunities, strategies and resources to address these requirements
- utilise the framework to consider how the elements and service requirements can align with any developing general cancer or gynaecological cancer service capability frameworks that are appropriate for the jurisdiction.
The National Gynaecological Cancers
Service Delivery and Resource Framework

Goals
- All women with a suspected (i.e. with symptoms indicative of a high risk of cancer) or actual gynaecological cancer have access to a comprehensive multidisciplinary team led by a gynaecological oncologist to provide high-quality management based on the best available evidence and tailored to women’s needs to achieve the best outcome for each woman.
- All women in the community have access to high-quality prevention, screening and surveillance strategies appropriate to their level of risk of specific gynaecological cancers.

Guiding principles
- The provision of woman- (and family-) centred care underpins all service delivery.
- Service delivery is guided by a wellness and empowerment philosophy that encourages women and their families to be actively involved in their care and decision-making across the pathway of care.
- All women have access to safe, high-quality multidisciplinary clinical and supportive care based on the best available evidence and tailored to women’s individual needs across the pathway from diagnosis to survivorship or palliation.
- Priority is given to ensuring and supporting women’s access to high-quality treatment through centralised specialist services. Where appropriate and in women’s best interests, opportunities to access aspects of care as close to home as possible will be optimised.
- Services are supported to provide care that is informed by continuous quality improvement through regular monitoring and reporting of key quality measures including women’s outcomes.
- Networks of organisational structures and processes are in place to support service delivery and referral between the different service models and across service sectors.
- Service development must optimise the best use of valuable resources both now and into the future.
Context

The multidisciplinary team

The National Framework strongly endorses the principle that good multidisciplinary care is the cornerstone of optimal cancer care and facilitates effective treatment planning, adherence to evidence-based guidelines and care coordination. The multidisciplinary team for managing all women with a gynaecological cancer across the care pathway includes the following disciplines:

- gynaecological oncologist (lead role)
- gynaecologist
- medical oncologist with expertise in gynaecological oncology
- radiation oncologist with expertise in gynaecological oncology
- radiologist with expertise in gynaecological oncology
- specialist palliative care providers
- genetic and genetic counsellors
- other medical specialists such as fertility and menopause specialists
- general practitioner
- nurse(s) with specialist knowledge in gynaecological oncology
- allied health services including:
  - social workers
  - dietitians
  - physiotherapists
  - lymphoedema practitioners
  - pharmacists
  - psychologists and psychiatrists
  - psychosocial counsellors
  - spiritual and pastoral care providers
- other service providers such interpreters, Aboriginal health workers and other community providers

This list is not exhaustive (see the Glossary [Appendix A] for key definitions).

While the multidisciplinary team may vary depending on the service context and pathway point, multidisciplinary care is essential for the achievement of high-quality care as outlined in the National Framework.

Who develops gynaecological cancers?

Gynaecological cancers represent a heterogeneous group of cancers that affect women’s reproductive and associated organs. In 2015,1 4193 Australian women were diagnosed with a gynaecological cancer of which:

- 1830 (43%) were cancer of the uterus
- 1274 (30%) were cancer of the ovary or related organs
- 734 (17.5%) were cancer of the cervix
- 355 (8.5%) were cancers of the vulva, vagina or placenta.

In 2015, 1562 women died of a gynaecological cancer, 58% (908) of whom had cancer of the ovary or related organs.

The majority of women with cervical, endometrial or vulval cancer are diagnosed with early disease and will be potentially cured of their disease. Over 60% of women with ovarian cancer are diagnosed with advanced disease.2

Table 1 summarises the current average incidence and the 2015 projected incidence of gynaecological cancers nationally and by state and territory.

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Average annual number of women with gynaecological cancer 2001–2005</th>
<th>Projected numbers of women with gynaecological cancer in 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>3994</td>
<td>5228</td>
</tr>
<tr>
<td>NSW</td>
<td>1315</td>
<td>1636</td>
</tr>
<tr>
<td>Victoria</td>
<td>1029</td>
<td>1330</td>
</tr>
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<td>1071</td>
</tr>
<tr>
<td>Western Australia</td>
<td>378</td>
<td>517</td>
</tr>
<tr>
<td>South Australia</td>
<td>329</td>
<td>492</td>
</tr>
<tr>
<td>Tasmania</td>
<td>100</td>
<td>129</td>
</tr>
<tr>
<td>ACT</td>
<td>58</td>
<td>76</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>27</td>
<td>43</td>
</tr>
</tbody>
</table>

Regional and rural women

- Overall cancer survival is lower in all people with cancer living in regional Australia.4
- NSW data indicated that the five-year survival for women with cervical cancer from rural and remote Australia was 52% compared with 76% of women living in or closer to metropolitan or major regional centres.4
- Aboriginal and Torres Strait Islander women
  - Aboriginal and Torres Strait Islander women have an increased incidence of cancer of the cervix and related organs.5
  - Clusters of vulval cancer and vulvar intra-epithelial neoplasia have been identified in young Aboriginal women living in remote areas of the Northern Territory.6
  - Aboriginal and Torres Strait Islander women with cervical cancer are 5.2 times more likely to die of their disease than non-Indigenous women.7
  - Although improving, the participation rates in cervical screening are lower in Aboriginal and Torres Strait Islander women.8

Women with gestational trophoblastic disease (including hydatidiform mole)

- This condition (GTD) includes a series of disorders in which there is abnormal growth of placental tissue that may spontaneously resolve, cause local invasion or metastasis and can result in death.
- Hydatidiform mole affects approximately 1 in 1000 pregnancies worldwide with some geographic variation – a higher incidence is reported in Asian countries.
- Evidence from Victoria indicates an incidence of 1 in 880 pregnancies with approximately 110 new Victorian cases registered with GTD each year. This incidence may in part reflect Victoria’s large immigrant population from Southeast Asia.
- Stakeholders agreed that these women should be routinely referred to specialist gynaecological oncologists and/or the multidisciplinary team for advice and assessment. While Victoria is the only state currently with a GTD registry, there were mixed views on both the need for such registries and whether they should be state or national. Further investigation of the merits of a national GTD registry is required.

Women’s needs

‘With a hysterectomy your fertility is compromised and there is a strong feeling that society’s perception of women’s worth is related to having children’ – so if you can’t have children what is your life worth? You need to go through a process of redefining yourself.’11

While many of the needs of women with a gynaecological cancer are similar to those facing any cancer diagnosis, the specific and intimate nature of gynaecological cancers, with their focus on reproductive and sexual organs, may present additional challenges to women’s sense of self and make them particularly vulnerable both during and following treatment.

Many of women’s needs are common across all pathway points.

Times of particular vulnerability include:

- time of diagnosis
- discharge from hospital and during any ambulatory treatment phases
- completion of treatment and moving into long-term survivorship
- recurrence
- diagnosis of incurable disease and transition or referral into palliative care.

The specific needs of women include:

- timely access to services, in particular to avoid unnecessary delays in diagnosis and management
- optimal clinical and multidisciplinary management according to best practice guidelines
- access to a ‘safe’ physical, emotional and cultural environment
- well-coordinated care
- access to optimal supportive care including:
  - information provision and decision-making
  - assessment and management of short- and long-term physical side-effects of treatment
  - provision of psychosocial care in response to the assessment of emotional, psychological, social and spiritual needs
- provision of practical support
- support and information to assist with psychosexual and fertility issues.
"I was encouraged to seek further information and support but was not given directions on where to go to find it. It felt overwhelming and was difficult to wade through what was helpful and accurate and what was not."

Appendix E considers each of the specific areas of need in more detail.

The needs of specific groups of women

There is a degree of commonality of needs among all women with gynaecological cancers regardless of background; however, for some women a different geographical, cultural, social or linguistic background may magnify needs or give rise to specific issues. Other women may be particularly vulnerable because of specific life experiences including sexual assault, disability and past or current mental health problems. For each woman, consideration must be given to her unique set of beliefs, values, life experiences and preferences and an approach to care tailored accordingly.

Regional and remote women

Most women with a gynaecological cancer from regional or remote areas currently receive all or most of their treatment in a metropolitan centre. This may result in a significant burden of travel or relocation. Particular issues and needs raised for these women include:

- the need to increase women’s awareness of symptoms and the need to prioritise their own health (particularly for women on the land)
- the need for improved access to more local diagnostic services where appropriate and the potential for shared care (e.g. some local treatment and follow-up) in some areas
- the financial burden and “culture shock” of being treated within a major city
- the need for improved access to adequate accommodation and travel assistance
- balancing treatment needs with home and work duties for women and family members
- the need for enhanced and timely communication with local service providers (GPs, local hospitals and community-based services) particularly following discharge
- the need for care planning to anticipate deterioration or impending death to optimise women being cared for within their own communities.

Aboriginal and Torres Strait Islander women

While a relatively small population,10 the experiences and needs of Aboriginal and Torres Strait Islander women may be quite diverse depending on where they live, e.g. within metropolitan and large regional centres or in smaller rural or remote communities. Of particular importance is the privacy and sensitivity of women’s reproductive health and sexuality which are seen as ‘women’s business’.

Specific needs of Aboriginal and Torres Strait Islander women include:

- culturally appropriate preventive health information about women’s business
- the need for best practice clinical care and a flexible service system that takes into consideration the cultural beliefs, values and practices of Aboriginal and Torres Strait Islander women, their family and community including:
  - understanding the obligations of women to fulfil their community roles
  - understanding the role of the family and community within decision-making
  - access to Aboriginal health workers and ‘cultural brokers’ to facilitate culturally appropriate support for women within health services and the community
- access to women service providers as required
- access to female interpreters for women who speak a traditional language
- Improved preparation for:
  - women and their support person from regional and remote areas about the potential diagnosis and length of stay within the city
  - service providers to respond to regional and remote women’s needs
- the need to address specific practical barriers to successful treatment including:
  - costs of specialists and medications
  - the need for appropriate accommodation and transport assistance for women and their support person
  - support to optimise women’s adherence to the recommended treatment over time
- timely recognition of the needs of women with advanced disease to:
  - enable culturally appropriate conversations with the woman and the community to prepare for her impending death
  - enable women to ‘return to country’ prior to their death
  - negotiate a clear plan for local care with health services and the community
- links with generic or specific support services including Aboriginal health and community services and cancer support programs or services for Aboriginal and Torres Strait Islander people with cancer and their families.

Women from culturally and linguistically diverse backgrounds

For women from culturally and linguistically diverse (CALD) backgrounds, their experiences of health and illness and understanding of the Australian health system may be contingent on their cultural background, language skills, length of time in Australia and experiences prior to migration which may include refugee experiences. Particular needs include:

- awareness and understanding of diverse cultural and spiritual beliefs and practices for individual women and families including beliefs about cancer, illness, fertility and sexuality and underlying beliefs of ‘shame and fear’ around a cancer diagnosis
- the need to increase awareness of:
  - preventive health and cervical cancer screening
  - symptoms and early presentation for diagnosis
  - understanding of the Australian health system
- access to female providers for gynaecological care for at least some women
- access to information provided in a culturally sensitive manner including:
  - access to interpreters for all critical consultations
  - access to supplementary information in an appropriate language and medium
- links with generic or specific CALD support services including:
  - ethno-specific support organisations
  - specific spiritual providers
  - cancer support programs or services for different language groups
- wherever possible, access to service providers from similar cultural and language backgrounds.

The service context

‘During treatment and the trauma of a life-threatening illness, the most important thing for me and my family was to put our trust in the hands of the life savers – the medical team. But as time progressed, I needed help in making decisions but I didn’t really understand that. Being given information about the different services and support systems that one may need to lean on during the cancer journey would have been beneficial in many ways.’

Women at risk of or with a gynaecological cancer currently access a wide range of generalist and specialist providers within the public or private sectors across Australia and require confidence in the medical team and access to an array of other services. Currently women with a gynaecological cancer are managed in the following service settings:

- Specialist gynaecological cancer services: these ‘specialist centres’ provide care to a large number of women with gynaecological cancers, have strong multidisciplinary teams and processes, offer the full range of treatment modalities on site or in close location and have good access to clinical trials and research and to specialist nursing and supportive care service providers.
- Other metropolitan services: these may provide some but not all aspects of care to smaller numbers of women. Services may be supported by individual gynaecological oncologists and some may have their own multidisciplinary processes or are linked in with a centralised multidisciplinary team. However, a more linear model of multidisciplinary care with sequential referral to other service providers may occur with more limited formal multidisciplinary treatment planning. There is more limited access to nursing and supportive care providers with specialist knowledge of gynaecological cancer.
- Private services: these may provide services to varying numbers of women and have variable access to multidisciplinary treatment planning. A more linear or informal model of multidisciplinary care may occur. Lack of access to supportive care providers within private services may result in some private patients being treated in the public sector to ensure access to the full range of required services.
**Regional services** that may have a range of different approaches including:
- mixed centralised and local service models where some treatment or care is provided in a metropolitan service and some in regional services by local providers such as medical oncologists
- visiting specialist service models where a specialist or sub-specialist may visit a regional centre to provide aspects of care.

**Secondary consultation approaches** enable general service providers and other specialists such as gynaecologists to access specialists or sub-specialists for advice and facilitation of appropriate care and referral. While there is greater consistency in access to multidisciplinary care and a range of services and service providers in specialist gynaecological cancer services, there appears to be significant variation in practice where gynaecological cancer services are offered in more generalist environments.

The key service providers involved in the management of women with gynaecological cancers are listed under the multidisciplinary team (see Context page 8) with role definitions being included in the Glossary (Appendix A).

**Drivers for change**
A number of factors driving the need for change underpin the National Framework.

**The broader health service context and reform agenda**
Future gynaecological cancer services and workforce needs cannot be considered in isolation from the broader health service context including:
- the burdening costs of health care
- the complex mix of and interface between public and private services leading to increasing fragmentation of services
- the increasing costs of health care
- the increasing pressure on inpatient beds and the drive towards ambulatory care
- ongoing workforce issues
- jurisdictional differences in how health services are managed and funded.

Current health service reforms addressing these challenges aim to develop a sustainable, high-quality, responsive health system for all Australians now and into the future.12

**Funding mechanisms**
A number of funding mechanisms and challenges may influence service development and practice within the public and private sectors including:
- significant budgetary constraints as a result of increasing service demand and increasing costs of all health service delivery across services and sectors
- the shift towards increasing ambulatory care for cancer patients has not been matched by funding to support access to allied health within ambulatory treatment settings
- limited funding for allied health providers within private treatment services
- limited financial incentives to optimise multidisciplinary care planning in the public or private settings; some reports indicate that the Medicare Benefits Scheme (MBS) item numbers for multidisciplinary planning are not significantly influencing practice.13

**Increasing service demand**
The overall incidence of cervical cancer is expected to decrease over time with the introduction of the human papilloma virus (HPV) vaccine. However, the growth and ageing of the population will increase overall gynaecological cancer service demand. Other factors that may impact on service demand include:
- increasing obesity causing an increase in endometrial cancer
- improved ability to identify genetic mutations resulting in an increasing number of women identified as being at high risk of ovarian or other cancers requiring additional surveillance or risk-reducing surgery; this may gradually decrease the number of women with ovarian cancer
- increasing referral for pathology and radiology review.

**Factors increasing the complexity of cancer management**
These include:
- the diversity and complexity of the different gynaecological cancers and treatment requirements with complexity of treatment being compounded:
  - if women are elderly, have co-morbidities and/or are obese
  - with the increasing use of advanced laparoscopic surgical techniques
- the relative privacy and sensitivity around women’s reproductive organs
- the direct impact that gynaecological cancer and treatment may have on fertility, sexuality and early menopause and on other areas related to women’s identity
- the confronting and invasive nature of treatment such as brachytherapy.

**Variation in current practices**
There is clear evidence of high-quality care being experienced by women particularly in high volume ‘specialist centres’. However, there is evidence of variance in clinical practice within specialist centres as well as in other service settings that may impact on women’s experiences and outcomes including:
- the lack of timely referral to gynaecological oncology services
- variable access to multidisciplinary team planning processes
- variable access to coordination processes and resources
- variable use of imaging and other investigations
- significant variability in access to supportive care providers across the pathway of care
- limited access to a range of providers (nursing, allied health, diagnostic services) with specific expertise in gynaecological cancer in some settings
- variability in follow-up processes within and across services.

**A stretched workforce**
Factors influencing the overall healthcare workforce include:
- the ageing of the general population and the workforce
- increasing sub-specialisation resulting from changing technologies leading to increasing fragmentation of the overall workforce
- competing demands for labour across the whole workforce and the general workforce intentions for more part-time work with more flexible work environments and a stronger emphasis on work—life balance.14

Within cancer care, there is increasing evidence that access to specialist or sub-specialist skills will improve outcomes for many cancer populations including women with gynaecological cancer.15,16

Factors increasing service demand include:
- improving referral of women with a suspected or confirmed gynaecological cancer to gynaecological oncologists
- the reducing surgical skills of obstetricians and gynaecologists with the trend to more medical management of general gynaecological conditions. This is leading to increased referral of women at low risk of a gynaecological cancer or women with complex obstetric or benign conditions requiring complex surgery; in one service in 2009, the average number of non-cancer cases per month requiring surgery by a gynaecological oncologist almost equalled the cancer demand.17
- significant service gaps in access to gynaecologists in regional and rural Australia.18

Other medical specialties such as medical and radiation oncology, palliative care medicine, radiology and pathology are also experiencing significant workforce issues. For example, recently published workforce reports highlight the current and projected national service gaps in medical oncology and significant workload issues for pathologists.19,20
Balancing access, quality and efficiency

There is clear emphasis in healthcare reform to improve access and equity issues for all Australians. The geography of Australia and the relatively small number of women with a gynaecological cancer presents particular challenges for service development to respond to the needs of regional and remote women. Future service planning must balance:

- the need for women to access quality services as close to home as possible, and
- optimising the most efficient use of specialist and sub-specialist resources.

Given the relatively small number of women with a gynaecological cancer, few regional centres have enough service volume to develop their own specialist gynaecological cancer service. For many women, access to a quality rather than a local service is the priority.

Currently some gynaecological oncologists provide visiting surgical services to a small number of regional centres with some evidence that these services have limited sustainability. In addition, regional services may be no more accessible for women living some distance away or for women requiring urgent treatment. Travel may add an additional burden for specialists or sub-specialists. The National Framework therefore considers the best use of valuable resources.

Limited evidence to inform service delivery models

The lack of high-level evidence in some areas has impacted on the development of this National Framework including:

- the appropriate workforce numbers for different disciplines involved in caring for women with gynaecological cancer that takes into consideration the Australian context
- the proportion of women who have a delayed diagnosis or who are not referred to gynaecological oncologists in a timely manner
- any variation in outcomes for some women depending on the region, volume of cases or the service delivery model
- the level of demand on gynaecological oncologists nationally to provide surgical management for women with non-cancerous conditions.

Opportunities for change

A number of opportunities exist to strengthen gynaecological cancer services for women.

Health service workforce reform

National, state and territory governments are making significant commitments to address workforce shortages including:

- workforce planning and research
- education and training
- innovation and reform.

In addition, specific professional colleges are taking an active role in reviewing their workforce and training requirements that will impact on gynaecological cancer services. This includes RANZCOG, the Medical Oncology Group of Australia (MOGA) and the Royal College of Pathologists of Australasia (RCPA).

Cancer reform agendas

Most states and territories have embarked on significant cancer reform agendas to enhance cancer services around Australia. A recent Commonwealth initiative has also allocated significant funding to support the development of regional cancer centres. This will result in increased capacity within regional centres and in the future may facilitate better local access to quality services for women with gynaecological cancer.

Other health service reform

The current environment of healthcare reform may provide new opportunities to strengthen cancer care services overall including those for women with a gynaecological cancer. Established or new programs or initiatives that may be of relevance include:

- a National Health and Hospitals Network for Australia’s Future Health Taskforce
- the Medical Specialist Outreach Assistance Program which aims to strengthen service access to people living in rural and remote areas of Australia
- the Indigenous Chronic Disease Initiative which links with the above program and has cancer as one of its five priority conditions
- the National E-health Strategy that includes the development of individualised e-health records, e-discharge, e-referral and e-medication management strategies.

Research and clinical trials funding

There is increasing emphasis on the need to support research and clinical trials. Cancer Australia and at least some states and territories have allocated funding to support all or some of the following:

- clinical trial and research infrastructure
- priority-driven research
- clinical trials not funded by industry partners.

Additional opportunities may arise in the future.
PART 1
Service delivery
elements and models
PART 1
Service delivery elements and models

1.1 Eight service delivery elements

1. ‘I shared a four-bed surgical ward in a public hospital for 13 days with patients recovering from various illnesses. For the whole of my stay there was at least one male patient. I found this unacceptable and felt very uncomfortable.’

‘Follow-up care should be broader than just checking for recurrence. There should be an “after care” program set up that addresses a range of issues and ensures that you are treated accordingly and get the support required.’

The eight service delivery elements that make up the National Framework to meet women’s needs consist of four pathway elements and four supporting elements that are required across the whole gynaecological cancer pathway, e.g. well-coordinated care.

Four pathway elements
1. Reducing risk and finding cancer early
2. The multidisciplinary team, management and support during treatment
3. Follow-up and survivorship
4. Advanced disease and palliative care.

Four supporting elements
5. A woman-centred environment
6. Supportive care
7. Coordinated care
8. Continuous quality improvement, consumer feedback, clinical trials and research.

Each service delivery element is based on evidence from the literature and from women’s and service providers’ perspectives.

Each element includes:
- An overarching objective that provides the service direction
- Specific service delivery components that identify key components of care within each element
- Supporting systems and processes required to address the service delivery component.

Table 2 provides a summary of each service element, the objective and the service delivery components required to meet the objective. Appendix F details the eight elements including the evidence-based rationale and supporting systems and processes for each component to facilitate service review.

### Table 2: The national service delivery framework – overview of the eight service elements

<table>
<thead>
<tr>
<th>The service delivery element</th>
<th>Objective</th>
<th>Service delivery components required to address the objective</th>
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</table>
| 1. Reducing risk and finding gynaecological cancer early | Women have timely access to services and programs to optimise prevention, risk reduction and early diagnosis of gynaecological cancers and related cancers. | - Timely access to prevention and risk reduction services for all women including:  
  - Health promotion strategies including nutrition, exercise and smoking practices  
  - HPV vaccination for young women  
  - Routine cervical cancer screening  
  - Management of women with a screen-detected abnormality  
  - Access to gynaecological cancer risk restitution, surveillance for women at high risk of gynaecological and other cancers.  
  - Timely and appropriate response to women presenting with symptoms suggestive of gynaecological cancer. |
| 2. Multidisciplinary management and support during treatment | All women with a confirmed or ‘suspected’ cancer or with recurrent cancer have access to best practice care including input from a gynaecological oncologist – that is in accordance with the best available evidence. | - A well-established and functioning multidisciplinary team with all key providers accessible.  
  - Multidisciplinary assessment and planning prior to major surgery for women with suspected cancer.  
  - Multidisciplinary treatment planning prior to women’s definitive surgery/after treatment for confirmed gynaecological cancer.  
  - Multidisciplinary management of women with recurrence.  
  - Communication of multidisciplinary planning outcomes.  
  - Optimal management of the cancer and acute complications and side-effects including pain management.  
  - Clinical trials availability and uptake. |
| 3. Follow-up and survivorship | After completion of treatment, all women receive appropriate and flexible follow-up care that is responsive to their needs, optimises the best use of available resources and is based on the best available evidence. | - Women have a clear follow-up plan after treatment.  
  - Follow-up care is provided by the appropriate service provider based on the woman’s condition, time since treatment completion and needs.  
  - Optimal assessment and management of short- and long-term side effects including fatigue, fertility, menopausal symptoms, emotional distress and practical concerns.  
  - Women with possible recurrence or other side-effects or needs have timely access back into the system, as needed.  
  - Optimal information flow between providers.  
  - Early referral to generalist and specialist palliative care providers. |
| 4. Advanced disease and palliative care | Women have access to treatment, symptom management and palliative care services to optimise their quality of life. | - Early referral to generalist and specialist palliative care providers.  
  - Services have access to specialist palliative care advice and support for optimising physical and psychosocial symptom management including pain management and psychological distress.  
  - Addressing the needs of women from diverse backgrounds with advanced disease and their families. |
| 5. Woman-centred care | Women receive care that is sensitive to the diversity of their individual needs and is provided in an appropriate, safe physical, emotional and cultural environment. | - The physical environment with particular attention paid to a woman-only environment.  
  - The cultural and emotional environment.  
  - Access to female service providers including clinical and non-clinical providers, e.g. interpreters. |
| 6. Supportive care | All women have access to supportive care that facilitates informed decision making and coping across the care pathway and includes a focus on information and physical, social, practical, psychological, psychosexual and spiritual needs. | - Screening for supportive care needs at key points in the service pathway.  
  - Responding to supportive care needs including:  
    - Information needs  
    - Specific physical needs such as fertility, menopausal issues, pain management, lymphoedema, continence issues  
    - Social and practical needs  
    - Emotional and psychological distress  
    - Spiritual needs  
    - Psychosocial needs.  
  - Addressing the supportive care needs of women from diverse backgrounds including:  
    - The provision of information resources that take into consideration the cultural, language and literacy needs of individual women.  
    - Strengthening service providers’ capacity to identify and respond appropriately to women’s supportive care needs within their scope of practice including good communication skills. |
| 7. Coordinated care | Women should experience their care as streamlined, timely, efficient and well-coordinated across the continuum of care. | - Optimising information flow between service providers.  
  - Organisational approaches to coordinating care within and between services and sectors including:  
    - Primary and acute services  
    - Public and private services.  
  - Access to key contact and coordinating roles. |
| 8. Continuous quality improvement, consumer feedback, clinical trials and research | All services providing care for women with gynaecological cancer are active participants in continuous quality improvement (including audit), consumer feedback strategies, clinical trials and research to improve outcomes for women. | - Continuous quality improvement activities.  
  - Consumer feedback to inform service improvement.  
  - Clinical trials available and uptake enhanced.  
  - Strengthened research capacity to guide future clinical management and service improvement. |
1.2 Supporting flexible and robust service models

**Objective**

High-quality gynaecological cancer services are developed or strengthened in accordance with agreed service models and organisational arrangements within and across jurisdictions, based on women’s needs and overall service demand.

To ensure women are managed by high-quality services based on the eight service elements, consideration must be given to service planning and developing the flexible but robust organisational arrangements and linkages required to meet local service demand.

This presents particular challenges across Australia because of:
- the Australian geography and differences in population within states and territories
- the relatively small number of women with gynaecological cancer
- the relatively small specialist and sub-specialist workforce
- the complexity and variation of treatment requirements dependent on the type of gynaecological cancer
- the variation in the level and degree of centralisation of specialist health services within the different jurisdictions.

Future service planning requires consideration of the needs of women to access high-quality services balanced against optimising local access (i.e. treatment as close to home as possible) and the most efficient and safe use of specialist and sub-specialist resources.

Of paramount importance is access to safe, high-quality care to optimise women’s outcomes. To ensure this:
- **all women** with a gynaecological cancer will require access to specialist skills in gynaecological oncology
- **many women** living in metropolitan areas may need to access specialist services some distance from their homes
- **all women** living in regional, rural and remote Australia may need to travel significant distances to specialist services for at least some aspects of their care. They will require transport and accommodation support while away from home.

Using a tiered approach, Figure 2 provides more specific advice on the required approaches for all, many, some or few women with a gynaecological cancer.

Using this framework as a guide to develop services for the future, each state or territory with local stakeholders will need to consider and agree on:
- the future service configuration and mix for their jurisdiction
- the specific requirements within different service approaches
- how current service approaches may be strengthened to achieve the requirements of the overall service model for each jurisdiction.

This will depend on:
- the current and future population needs and service demand
- current health service configurations and approaches to specialist service provision (including cancer service and palliative care service models or networks), service delineation and current or developing service capability frameworks within jurisdictions
- available resources and current and projected workforce requirements
- balancing the advantages and disadvantages of the different service models (see Appendix G) in the jurisdictional context and finding the best fit that is agreed by policy makers, clinical stakeholders and consumers.

To facilitate local decision-making, the National Framework considers the following elements of service delivery:
- the volume or caseloads for multidisciplinary teams and services
- service models for the future
- support structures or organisational networks that will facilitate best practice.

**Figure 2**: The tiered approach to service levels for providing care for women with suspected or confirmed gynaecological cancer

- **All women** with suspected cancer (at high risk) require:
  - referral (or access) to a gynaecological oncologist
  - access to multidisciplinary treatment planning.
- **Following treatment all women** should be considered for more local follow-up care where and when appropriate.
- **Many or some women** will require treatment within centralised specialist cancer services. This includes all women having:
  - concurrent chemotherapy and radiotherapy
  - external radiotherapy and brachytherapy at the same service.
- **Some women** will require some treatment within centralised centres but other treatment may be undertaken through more regional services, e.g. surgery in a centralised service but chemotherapy may be provided more locally.
- **Some/few women** requiring less complex management (e.g. surgery alone) may access treatment within a regional or more local service provided by a visiting specialist, e.g. gynaecological oncologist (after multidisciplinary review).
1.3 Optimising caseloads for multidisciplinary care

Principles to guide service development based on service volume

- Individual gynaecological oncologists should be providing surgical management to a minimum of 75 new cases per annum. This may be achieved through their employment in one service or across several public or private services.
- All large specialist gynaecological cancer services (specialist centres mainly in tertiary settings) should be treating 150–250 new cases per annum.
- In small states, specialist centres should optimally be managing at least 100 new cases per annum.
- Smaller metropolitan services and regional services with a visiting gynaecological oncologist should optimally manage 100 new cases per annum.
- All gynaecological cancer services should be supported by a minimum of two gynaecological oncologists. There should be no services supported by solo gynaecological oncologists.
- A service treating over 200 women per annum should be supported by at least three gynaecological oncologists.
- High-volume centres should undertake the most complex surgery.
- The complexity of surgery undertaken in other environments is dependent on:
  - the overall annual volume
  - the availability of the range of clinical support services such as intensive care units and high-quality diagnostic services
  - the availability of appropriately skilled nursing and supportive care providers.
- Regardless of the gynaecological oncologists’ skills, services treating less than 100 women per year should perform less complex gynaecological cancer surgery. The smaller the service volume, the less complex surgery should be.

The above principles have been developed based on the best available evidence and consensus with key stakeholders and are considered the optimal caseloads for services to facilitate:
- multidisciplinary treatment planning processes and decision-making
- good multidisciplinary care during treatment (e.g. surgical care within smaller metropolitan or regional settings)
- the appropriate level of skills in individual practitioners and supporting services.

Patterns of care literature for managing gynaecological cancers reports a range of evidence that considers service volume (e.g. low, intermediate or high), service type (e.g. general/community, semi-specialist or tertiary), service provider volume and the level of specialisation (general surgeon, semi-specialist gynaecologist or specialist gynaecological oncologist). The varied evidence from published studies and UK guidance indicates:
- access to appropriate surgery was better in those services that treated 24–35 cases per year versus those that treated 11 or fewer women
- other definitions for hospital volume range include: high volume 20 or more patients, intermediate 10–19 cases and low volume 9 or fewer patients
- more limited evidence is available on the impact of a high-volume specialist provider, i.e., gynaecological oncologist within a low-volume or semi-specialist service, and the link between outcomes and multidisciplinary team planning within these settings
- an early ‘definitive’ study reported a decrease in the risk of death at five years for women with ovarian cancer treated in teaching hospitals. This was independent of optimal surgery and reflects the presumed benefit of multidisciplinary management
- the UK guidance indicates that gynaecological cancer centres should manage a minimum of 200–250 cancers per year.

Service mapping data (see Appendix H) and anecdotal evidence provide some indication of current volumes within specialist centres and within metropolitan and regional visiting specialist services. For example:
- from 11 individual specialist centres in the public sector, the average number of new cases per year was 167 (range 98 to 250, median 163); three centres exceeded 200 cases per annum
- in one jurisdiction providing care to just under 100 women per annum, surgery is undertaken by one gynaecological oncologist across one private and one public service
- four services with visiting gynaecological oncologists in metropolitan or regional areas indicated that the numbers of women undergoing major gynaecological cancer surgery ranged from 30 to 70 per annum.

Evidence of multidisciplinary team planning

Descriptions of current multidisciplinary treatment planning processes across specialist centres and visiting specialist services highlighted:
- fairly mature multidisciplinary team planning processes in most specialist centres
- multidisciplinary planning processes being burdensome in some high-volume specialist centres for at least some team members
- centralised multidisciplinary treatment planning meetings with women’s subsequent surgery being undertaken in public or private specialist services or in smaller metropolitan and regional services (with a visiting specialist)
- visiting specialist services with different approaches to addressing multidisciplinary planning processes including:
  - local multidisciplinary meetings with some but not all relevant team members
  - linkage of local providers with centralised multidisciplinary planning meetings in the host service of the visiting gynaecological oncologist using videoconferencing
  - women treated by the gynaecological oncologist within a regional service presented at a related centralised multidisciplinary treatment planning meeting. Local providers are not present and there are some challenges in accessing pathology slides and reports in a timely manner.

Providing multidisciplinary care

Multidisciplinary care includes all aspects of service delivery and not just treatment planning. While overall access to staff experienced in gynaecological cancers is available in specialist centres, consultations indicate that:
- there are more limited organisational structures and processes to support general staff, e.g., nursing staff involved in providing care to women at some services with visiting specialists or sub-specialists
- contractual arrangements with a visiting specialist provider may be considered the only requirement for the provision of quality care for women and their families.

Other factors for consideration include:
- the need for support for at least two gynaecological oncologists (and potentially other solo providers in other disciplines) who currently work as single practitioners within their service with limited access to on-call or annual leave relief
- the limited evidence on optimal service volumes for providers treating women with external radiotherapy and/or brachytherapy (see also Section 2.4 page 37)
- some anecdotal evidence that where a visiting service is provided for one specialist discipline, e.g., surgery, women may be referred to other unrelated services for chemotherapy or radiotherapy
- some evidence of regional women being referred to a specialist centre that is not closest to their home.

1.4 Service models for the future

Using the service volume principles, the National Framework builds on and strengthens current service approaches to propose the following service models for the future.

Regardless of the service model(s) developed, all services and providers of gynaecological cancer care must ensure that the eight service delivery elements are addressed in their services and practices to ensure high-quality care and optimal outcomes for women.

The specialist gynaecological cancer service model

Services are mostly located in capital cities or larger regional centres and provide services to large volumes of women (more than 150 women per annum) and are supported by at least two to three gynaecological oncologists. Optimally in smaller states, specialist centres should have a minimum caseload of 100 new cases per annum.

Within a strong multidisciplinary approach, these specialist centres offer comprehensive care with all treatment services available on site or in close proximity and provide access to a wide range of service providers including supportive care, family cancer clinics, clinical trials and research.
PART 1
Service delivery elements and models

While this model is the preferred approach, to optimise service access for women, this model should also demonstrate a strengthened use of shared care approaches (see below) to enhance local care for women where appropriate and safe to do so.

Visiting specialist service model
Services may be located in metropolitan or regional centres and provide services to smaller numbers of women. This model may be provided in different ways including:
- visiting specialist or sub-specialists providing specialist services within a more general metropolitan service with limited other services specific to gynaecological cancer. Ongoing care is provided by the visiting specialist or sub-specialists.
- visiting specialist or sub-specialists from outside the geographic area travelling to provide specific services with the host organisation and more generalist and specialist service providers (e.g. gynaecologists) supporting and underpinning the management and care of women in the absence of the visiting specialist.

The National Framework recognises that the visiting specialist model has some benefits in terms of more local access and reducing the service demand on specialist centres, including access to beds and other health service facilities. However, these services need to be strengthened to enhance the quality of care for women in accordance with the eight service delivery elements and be linked with a specialist centre.

Shared care models
"When leaving the initial treatment centre a discharge plan should include a referral and name of a local health professional who will assist in coordinating ongoing care."

Shared care models complement both the specialist centre and the visiting specialist models. With shared care:
- women may receive some aspects of care in specialist centres and, where appropriate, some care in more local services. This includes treatment with curative intent as well as access to local palliative care services if required.
- depending on the service context, visiting specialist models may be supported by shared care with other providers within the health service. Opportunities for shared care with other local providers in other sectors such as palliative care should also be maximised. Table 3 provides more detail of the proposed features of these three service models. Appendix G summarises some of the advantages and disadvantages of each approach.

Table 3: Key features of the three different gynaecological cancer service models

<table>
<thead>
<tr>
<th>Service model</th>
<th>Specialist centre model</th>
<th>Visiting specialist model</th>
<th>Shared care model</th>
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</thead>
<tbody>
<tr>
<td><strong>Key features</strong></td>
<td><strong>Key features</strong></td>
<td><strong>Key features</strong></td>
<td><strong>Key features</strong></td>
</tr>
<tr>
<td>Centralised services in capital cities or large regional centres, usually within major tertiary health services.</td>
<td>Specialists or sub-specialists provide specific services to smaller services in metropolitan or regional areas, e.g. gynaecological cancer surgery or chemotherapy.</td>
<td>Women are able to receive some aspects of care closer to home which may require specialist centres linking with:</td>
<td></td>
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<tr>
<td>Provide care to a large volume of women – 150+ new cases per year, with at least 2–3 gynaecological oncologists supporting the service.</td>
<td>The optimal minimum volume recommended is 100 new cases per annum per service.</td>
<td>– other specialist providers such as regional cancer centres or day oncology services</td>
<td></td>
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<tr>
<td>Optimally specialist centres in smaller states should have a minimum caseload of 100 new cases per year.</td>
<td>The host organisation provides a range of additional services to support and underpin the visiting service, e.g.:</td>
<td>– more generalist services such as gynaecologists or general practitioners</td>
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<tr>
<td>Manage the most complex cases as part of their service demand.</td>
<td>– local gynaecologists may provide initial pre-operative assessment, post-surgical care and follow-up services</td>
<td>– local specialist and generalist palliative care providers.</td>
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<tr>
<td>A strong multidisciplinary team planning approach.</td>
<td>– diagnostic services including radiology and pathology</td>
<td>– Specialist services that must be provided centrally may include most gynaecological cancer surgery and combined external beam radiotherapy with brachytherapy.</td>
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<tr>
<td>Treatment modalities are available on site or in close proximity at linked specialist services, e.g., radiotherapy centres.</td>
<td>– an appropriate environment and appropriately trained nursing and supportive care providers</td>
<td>Some or all of the other treatment modalities such as chemotherapy, external radiotherapy or follow-up care may be provided more locally.</td>
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<tr>
<td>Other comprehensive care with access to a wide range of service providers including supportive care, family cancer clinics, clinical trials and research.</td>
<td>– coordination of care.</td>
<td>All providers are part of the multidisciplinary team with appropriate linkages between local and/or centralised multidisciplinary processes.</td>
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</tr>
<tr>
<td>Have access to specialist gynaecological cancer nursing expertise to facilitate patient and staff education, optimise screening and assessment of women’s supportive care needs and help women navigate complex health systems.</td>
<td>In general less complex treatment is provided at these services with the complexity of care reducing dependent on service volume and the service context including facilities and support staff.</td>
<td>Clear communication between providers and a clear key contact for women.</td>
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<tr>
<td>Provide secondary consultation to other service providers across disciplines.</td>
<td>Depending on the service context, the visiting specialist may provide a range of related services, e.g. in addition to surgery a gynaecological oncologist may provide post-operative support within a regional service for a short period of time.</td>
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<tr>
<td>The number of specialist centres in each jurisdiction is dependent on the population.</td>
<td>Multidisciplinary planning may take place locally or optimally by linking with multidisciplinary planning meetings or processes in specialist centres using appropriate technology.</td>
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<td></td>
<td>Some treatment modalities (other than those provided by the visiting specialist skill) may be available locally or require travel to a specialist centre (see shared care model).</td>
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</table>
1.5 Establishing gynaecological cancer networks

Principles to guide structural arrangements

- Priority is given to ensuring women are offered care in the gynaecological cancer service closest to their home and appropriate to their needs (except where the woman’s preference is to be treated elsewhere).
- Each of the service models within a network is able to provide consistent quality care appropriate to the service context in accordance with the eight service delivery elements.
- Consistent practice is optimised with the use of common protocols and referral pathways.
- Formalised agreements or memorandums of understanding to guide a networked provision of services are developed through service executives and/or facilitated by relevant jurisdictional staff rather than only with individual clinicians.
- Networks include clinical arrangements led by clinical stakeholders and organisational arrangements supported by service executives.
- While the level of formalisation required is agreed at jurisdictional and service level, flexibility is also required to accommodate women’s individual needs.
- Networks include all aspects of care and not just ‘technical aspects of clinical care’ and include secondary consultation, professional development for more general nursing and supportive care staff and access to specialist and generalist palliative care skills.
- Strong, collaborative relationships are developed between service providers to optimise communication and support.
- Where some treatment services, e.g. surgery, are provided by a visiting specialist service, other treatments such as radiotherapy or chemotherapy should be provided locally if appropriate or through the same provider service or network, wherever possible. This will optimise information flow and continuity of care for women and families.

While there are some formal arrangements between individual services and service providers, current relationships are mostly informal. To facilitate improved outcomes for women and support for smaller multidisciplinary teams and/or services, there was stakeholder support for more formal organisational arrangements guided by the above principles.

One stakeholder highlighted the ‘hub and spoke’ model utilised within a US health service. The UK guidance for the organisation of gynaecological cancer services clearly outlines the importance of formal arrangements between their recommended service levels. 32

Managed clinical networks

Within the broader Australian healthcare context, given the challenges of geography, workforce issues and access to specialist and sub-specialist services, many jurisdictions are now developing clinical networks as a means to promote and develop better cooperation, collaboration and integration across services and the overall system. 32 Managed clinical networks have been defined as: linked groups of health care professionals and organisations from primary, secondary and tertiary care working in a coordinated manner, unconstrained by existing professional and organisational boundaries to ensure equitable provision of high quality effective services. 32

A range of benefits of managed clinical networks have been identified including:

- more involvement of patients and service providers in developing clinical services
- facilitation of health service and workforce reforms including developing new or expanded roles to address workforce shortages and increasing demand
- improved coverage of specialist services across geographical and political boundaries
- identifying and sharing scarce resources such as specialist practitioners
- sustaining vulnerable services and maintaining access where the requirements of training or sub-specialisation would otherwise mean the complete closure of services to the area. As such they facilitate standardising care and improving access.

While the National Framework proposes the development of formal organisational arrangements it does not determine how these structural arrangements may be best developed. This would be negotiated at a jurisdictional and service level guided by the agreed principles for structural arrangements.

Organisational networks for gynaecological cancer services

Given the challenges facing gynaecological cancer services and the potential benefit of more networked approaches to service development, there is the need to consider organisational arrangements to respond to different service contexts.

Figure 3 illustrates how services may be linked together to optimise care for women. Enhancing organisational arrangements between different services within the same jurisdiction or between jurisdictions and potentially across public and private sectors may have a range of benefits including:

- improved access to secondary consultation with a gynaecological oncologist or other specialists for generalist providers, e.g. GPs and other specialists such as gynaecologists
- improved access to peer advice and support between different specialist or sub-specialist disciplines across health services including palliative care
- the implementation of agreed referral pathways and processes
efficiencies in multidisciplinary team planning processes
- enhancing lease coverage and succession planning for gynaecological oncologists and other specialist skills in small services
- facilitating skills development and knowledge for generalist providers
- facilitating improved access for women to clinical trials and other research.

27
PART 2

Workforce development
PART 2
Workforce development

2.1 Developing a skilled and supported workforce
The National Framework aims to develop service capacity by identifying the specific skills required within the multidisciplinary team to respond to the current and future needs of women with gynaecological cancers across Australia. As all women with a gynaecological cancer require access to highly specialist skills for critical aspects of management, Part 2 considers the resources and skills of specific specialist and sub-specialist disciplines as well as the skills required by more generalist providers. The identification of specific skills in some areas may be transferable to other providers within multidisciplinary gynaecological cancer teams or broader health teams.

The following specific disciplines are addressed:
- gynaecological oncologists
- gynaecologists
- medical and radiation oncologists
- nurses
- pathologists
- radiologists
- general practitioners
- data managers and clinical trial support
- specialist and generalist palliative care providers
- supportive care providers (including:
  - social workers
  - psychologists
  - psychosexual health support
  - other supportive care providers
- Aboriginal health workers
- other providers

Other generalist or specialist providers (e.g. physiotherapists, lymphoedema practitioners and fertility or menopause specialists) may have contact with women at different points in the pathway. The additional competencies that these providers require to support women with gynaecological cancers are briefly addressed.

The many challenges in estimating the diverse workforce requirements for optimal gynaecological cancer care include:
- limited definitive evidence of resource requirements for specific disciplines that are applicable to the Australian context
- where gynaecological cancer is the significant component of the work role, it is somewhat easier to estimate current and future resource requirements. It is more difficult to develop estimates for roles such as radiation and medical oncologists for whom gynaecological cancers may be only part of a broader cancer role
- workforce shortages in a wide range of disciplines involved in the care of women with gynaecological cancers.

Some stakeholders consulted for this National Framework considered quantification of workforce requirements as a useful exercise to guide training strategies, service planning, benchmarking of current resources and providing evidence to support requests for additional resources. Others, however, considered that establishing optimal resource requirements was likely to set expectations that cannot be met in the current health environment where there is strong competition for scarce resources.

The National Framework has adopted the following approach:
- for gynaecological oncologists only, current and future specific resource requirements have been identified along with potential challenges in achieving these levels
- the skills and expertise needed by other providers and mechanisms and processes by which these skills can be attained have been considered
- where appropriate, the minimum caseload considered to be appropriate to facilitate safe care has been quantified
- a focus on optimising the best use of available resources and avoiding duplication of services
- while some specialist and sub-specialist disciplines will provide discipline-specific skills to the management of women with gynaecological cancers, they will also require a more general skill base to support other elements of care – in particular, general supportive care and palliative care skills
- in line with the proposed gynaecological cancer networks, each professional discipline must ensure a networked approach to provide leadership and support for professional colleagues across services.

2.2 Gynaecological oncologists
Future resource requirements for gynaecological oncologists
Based on consideration of multiple factors, the National Framework identifies a goal of 52 certified gynaecological oncologists by 2015. This is consistent with the UK ratio of two gynaecological oncologists per 200 new cases per annum.

The sub-specialty of gynaecological oncology has been established in Australia over the past 20 years, with Australia being one of the international leaders in developing sub-specialty training. This three-year training program is currently commenced after completion of at least five years of RANZCOG specialty training for obstetrics and gynaecology.

A number of specific and broader issues need to be considered in addressing future gynaecological oncology workforce requirements.

Current practice and workforce estimates
Within Australia there are currently 43 certified gynaecological oncologists based in one of the six Australian states. A 1998 report into the obstetrics and gynaecology workforce highlighted current and recommended future ratios of sub-specialists to the population of women aged 15 years and over. These were:
- the then current ratio of gynaecological oncologists to female population of 0.3:100,000
- a recommended future ratio of 0.4:100,000 (this was based on US rates at the time and this ratio is still considered to be an appropriate benchmark).[27]

The current Australian workforce of 43 certified gynaecological oncologists meets or exceeds the recommended ratio of 0.4:100,000 across jurisdictions:
- nationally and in four states, there is a ratio of 0.5 gynaecological oncologists per 100,000 women aged 15 years and over
- in NSW the ratio is 0.6:100,000
- in Victoria the ratio is 0.4:100,000.

These figures assume that all gynaecological oncologists are working full-time in their gynaecological cancer role. Some may be working part-time or have other responsibilities within a full-time workload.

UK guidance recommends that a ‘gynaecological cancer centre’ manages a minimum of 200–250 new cases per annum (serving a total population of 750,000–1 million) with a minimum of two gynaecological oncologists per centre.[30] The figure of 43 gynaecological oncologists appears to align well with this recommendation (42 would be required nationally based on 200 new cases per annum).

However, a range of challenges to workforce capacity require further consideration.

The Australian geography
There are significant challenges associated with providing highly specialised services to a relatively small population of women spread over a vast continent.

Increasing number of women with a gynaecological cancer
The AIHW predicts a 24% increase in cases of gynaecological cancers from 2005 to 2015 (see Section 2.1). There is also an increasing number of women who are surviving longer and presenting with recurrent gynaecological malignancies.

An ageing workforce
Twenty-one per cent of the current practising gynaecological oncologists are at or over retirement age (65 years) or within one to five years of retirement age. The jurisdictions that are particularly affected include:
- Western Australia (two of four providers are at or approaching retirement age)
- Victoria (two of nine providers are at or approaching retirement age)
- South Australia (one of four providers is at or approaching retirement age).

Variable capacity to meet current demand
Some services and providers report being ‘very stretched’ with current demands. This was particularly the case in jurisdictions with lower numbers of gynaecological oncologists and/or a higher proportion of the workforce at or nearing retirement age.

Coverage in the ACT and Northern Territory
There are currently no gynaecological oncologists based in the ACT or Northern Territory.
Single-provider jurisdictions or services

There is currently only one gynaecological oncologist serving the Tasmanian community. A small number of mainland services (specialist centres or through visiting specialist models) are currently supported by only one gynaecological oncologist. These single-provider services are particularly vulnerable.

Succession planning and backfill

There is a need for a critical workforce mass to facilitate collegial support, family and other leave coverage and succession planning.

Increasing complexity of diagnostic and therapeutic techniques

There is an increasing use of advanced laparoscopic surgical techniques and other techniques requiring increased technology, resources and expertise.

The complexity of gynaecological cancer care

The physical and psychological morbidities and complex social and cultural factors impacting on the experience of women with gynaecological cancers require attention in an optimal environment.

Increasing non-cancer workloads

Increasing referral to gynaecological oncologists of women at low risk of cancer for assessment and increasing demand for access to advanced surgical skills to manage women with complex benign gynaecological conditions has been identified (see following box).

One specialist centre reported that in 2009 the monthly average number of women seen with complex benign conditions almost equaled that of women with newly diagnosed gynaecological cancers.43

These challenges impact on the capacity to meet existing demand across Australia and also pose significant challenges for future growth and workforce planning.

Broader RANZCOG workforce issues impacting on the gynaecological oncology workforce capacity

There are significant challenges facing the overall obstetrics and gynaecology workforce in Australia which RANZCOG is currently addressing. These issues include:

- the need to provide a general specialist workforce in obstetrics and gynaecology, underpinned by a well-trained sub-specialty workforce
- the changing practices within gynaecology resulting in fewer surgical procedures and fewer specialists with high-level surgical skills to manage complex cases
- challenges with current training programs that cover both obstetrics and gynaecology including:
  - ensuring adequate surgical experience for trainees
  - trainees abandoning one or another half of their specialty on attaining their fellowship.44

A detailed review process is being undertaken by RANZCOG to inform any changes that may be recommended to future training of the overall obstetrics and gynaecology workforce.

The future directions taken by RANZCOG, if they influence the ‘benign’ surgical workload, will provide some increase in capacity for the gynaecological oncology sub-subspecialty.

Future service requirements

By 2016 the expected Australian population of women aged 15 years and over is estimated to be just over 9.8 million.45 It is also estimated that 5,228 gynaecological cancers will be diagnosed in 2015.46

Table 4 identifies a range of estimates of the number of gynaecological oncologists that would be required by 2015 according to a range of ratios for the whole population or for the expected number of new cancer cases.

<table>
<thead>
<tr>
<th>Ratio of gynaecological oncologists to 100,000 women aged 15 years and over</th>
<th>2016 projected population of women aged 15 years and over (n=9,806,487)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996 recommended ratio of 0.4:100,000</td>
<td>Estimated number of gynaecological oncologists required</td>
</tr>
<tr>
<td>0.4</td>
<td>39</td>
</tr>
<tr>
<td>Current national ratio of 0.5:100,000</td>
<td>49</td>
</tr>
<tr>
<td>NSW ratio of 0.6:100,000</td>
<td>58</td>
</tr>
<tr>
<td>Ratio of gynaecological oncologists to estimated new cases in 2015 (n=5,228)</td>
<td>Estimated number of gynaecological oncologists required</td>
</tr>
<tr>
<td>UK ratio of 2 gynaecological oncologists per 250 new cases</td>
<td>44</td>
</tr>
<tr>
<td>UK ratio of 2 gynaecological oncologists per 200 new cases</td>
<td>52</td>
</tr>
</tbody>
</table>

Based on the 1996 recommended ratio, it appears that current resources are adequate to meet future service demand. This does not match evidence from the field about increasing service demand, stretched resources and other workforce challenges.

To address these challenges, the National Framework proposes that a goal be set of 52 certified gynaecological oncologists by 2015 which is consistent with the UK ratio of two gynaecological oncologists per 200 new cases per annum. Table 5 shows the current workforce and the required gynaecological oncology workforce by jurisdiction by 2015.

In working towards these goals, particular priority must be given to:

- succession planning and continuity of service provision for retiring gynaecological oncologists
- providing additional gynaecological oncologist support in Tasmania
- addressing strategies to address access issues for the ACT and Northern Territory.

Key strategies that will contribute to these goals include optimising current and future workforce capacity through:

- relieving the non-cancer workload where possible for gynaecological oncologists through addressing surgical expertise in the broader RANZCOG workforce (see preceding box)
- reviewing the gynaecological oncologists’ role in general colposcopy services and ongoing follow-up services
- considering other role redesign initiatives to provide the optimal match of expertise to need within the multidisciplinary cancer workforce.

The goals will also need to be adjusted through an active review process of:

- total full-time equivalents available for gynaecological cancer services by jurisdiction
- service demands experienced in each jurisdiction
- most current cancer incidence data
- changing workforce requirements, e.g. expected and unexpected attrition.
PART 2
Workforce development

Table 5: Estimated number of gynaecological oncologists by jurisdiction by 2015

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Average number of gynaecological cancers 2001–05</th>
<th>Current number of gynaecological oncologists</th>
<th>Expected number of gynaecological cancers 2015</th>
<th>Number of gynaecological oncologists needed based on UK ratio of 2 per 200 new cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>4193</td>
<td>43</td>
<td>5228</td>
<td>52</td>
</tr>
<tr>
<td>NSW4</td>
<td>1373</td>
<td>17</td>
<td>1636</td>
<td>17</td>
</tr>
<tr>
<td>ACT3</td>
<td>58</td>
<td>76</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Australia4</td>
<td>356</td>
<td>4</td>
<td>444</td>
<td>5</td>
</tr>
<tr>
<td>Northern Territory4</td>
<td>27</td>
<td>4</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Queensland</td>
<td>758</td>
<td>8</td>
<td>1071</td>
<td>10</td>
</tr>
<tr>
<td>Tasmania</td>
<td>100</td>
<td>1</td>
<td>129</td>
<td>2</td>
</tr>
<tr>
<td>Victoria</td>
<td>1029</td>
<td>9</td>
<td>1330</td>
<td>13</td>
</tr>
<tr>
<td>Western Australia</td>
<td>378</td>
<td>4</td>
<td>517</td>
<td>5</td>
</tr>
</tbody>
</table>

Current and future training requirements

In 2011 there are eight trainees within the RANZCOG gynaecological oncology sub-specialty training program in Australia. If these, the expected time to completion is estimated to be four trainees in 2011, three in 2012 and one in 2013. If these trainees qualify and practise in Australia, this would cover the expected current attrition through retirement. However, it is not known where newly qualified gynaecological oncologists will practise and whether they will fill the identified gaps in jurisdictions.

To meet the future goal of 52 gynaecological oncologists by 2015, a minimum of eight additional certified gynaecological oncologists would need to be recruited from overseas or trained in Australia in addition to the numbers required to meet expected and unexpected attrition during that time period.

Achieving this level of growth is likely to pose many challenges. The following barriers to the uptake of sub-specialist training have been identified in consultations:

- funding challenges for sub-specialty training positions within some health services
- the demands of sub-specialty training—three years of training after completion of the five years required for obstetrics and gynaecology
- limited guarantees of positions once trained given the relatively low service demand and health services’ financial constraints
- other medical specialties or sub-specialties are seen to be more financially rewarding
- the desire for work-life balance with reduced working hours
- the increasing feminisation of the gynaecological workforce may result in a demand for more flexible training and work options to balance family aspirations
- some examples of available training positions not being filled by local trainees
- overall reduction in interest in specialising in obstetrics and gynaecology.

Addressing these challenges will require considerable collaboration and concerted effort between RANZCOG, the Australian Society of Gynaecologic Oncologists and the jurisdictions to:

- achieve the longer term goal
- address more immediate service demands within specific jurisdictions

- develop and implement innovative workforce strategies to address service demand and to optimise the best use of the available sub-specialist skills.

2.3 Gynaecologists

Gynaecologists play a very important role in the gynaecological cancer pathway including:

- assessing and managing women with abnormal cervical abnormalities
- assessing women with symptoms that may be suggestive of gynaecological cancer
- referring women with gynaecological cancers (or with high risk criteria) to a gynaecological oncologist and supporting surgical management where appropriate
- providing follow-up care for at least some women.

Initial assessment of women and appropriate referral

Gynaecologists have an important role in providing high-quality assessment and management of women with pre-cancerous conditions and referral of women with a suspected or actual gynaecological cancer to gynaecological oncologists. In 2001, it was estimated that 97% of diagnostic colposcopies and virtually all treatments of women with screen-detected cervical abnormalities were carried out by specialist gynaecologists or trainees under their supervision.44,45 Based on Victorian data, we estimate that all colposcopies performed for women with screen-detected abnormalities, just under 2% of women had histologically proven invasive or micro-invasive cancer and 10% had cervical intra-epithelial neoplasia (Grade 3).46 Performance standards in colposcopy were described in 2001.46 The National Cervical Screening Program has funded RANZCOG to develop a quality project (C-Quip) to establish certification of colposcopy practitioners. This project includes the development of a web-based educational program and an audit of colposcopy practice. It is expected that certification processes will be available within the second half of 2011.47 Once successfully established, all colposcopy providers should be actively encouraged to participate in this important quality assurance program.
Specialist gynaecologists are also a key referrer of women with an actual or suspected gynaecological cancer to gynaecological oncologists. A recent study documented intended referral practices of both gynaecologists and GPs for a range of hypothetical clinical scenarios. Of the gynaecologists who responded to this study (n=404) some variation in referral practice was identified including:
- 25–30% of participants would not have referred women with a high probability of endometrial, ovarian or vulval cancer
- 25% of participants would not have referred women with Grade 1 endometrial cancer
- 40% would have referred women with a low likelihood of ovarian cancer; this would support anecdotal evidence from gynaecological oncologists about an increasing number of referrals of women at low risk of cancer.

In addition, consultation findings from this project identified some anecdotal examples of gynaecologists not referring women with a high risk of malignancy in a timely manner. The extent of this issue needs to be quantified.

To improve support for gynaecologists in the initial assessment and referral of women with a suspected gynaecological cancer, access to local or regional gynaecological oncologists was identified as a key enabler for gaining advice and facilitating appropriate and timely referrals. More formal access to secondary consultation may be particularly important for regional and rural gynaecologists working under very stretched conditions.

Gynaecologists’ role in surgical management

Given the burden on current gynaecological oncologists, there is a need to consider any future role for gynaecologists in providing relief to the system.

There is variable evidence of current approaches including:
- evidence from a New Zealand study in which following referral to the multidisciplinary team and being assessed in the multidisciplinary treatment planning process, at least some women with early clinical stage, low-grade endometrial cancer were referred back to their gynaecologist to have surgery
- some evidence of gynaecologists with an interest in gynaecological cancer working within specialist centres and currently providing aspects of surgical management within the context of a multidisciplinary team
- evidence of changing clinical practice for the management of some early cancers that results in more complex surgical management to improve women’s outcomes
- some local evidence of gynaecologists consulting with gynaecological oncologists about individual women and based on individual factors and pathology review undertaking the required surgical management
- where there are visiting gynaecological oncologists to smaller metropolitan, regional or interstate services, there is some evidence of local gynaecologists being very actively involved in:
  - assessing women prior to surgery
  - assisting the gynaecological oncologist in the surgery
  - being involved in multidisciplinary treatment planning
  - managing some or all of the post-operative care
- strong support by gynaecological oncologists for all women with a suspected gynaecological cancer (based on criteria in established guidelines) to be referred to a certified gynaecological oncologist for assessment and multidisciplinary care
- some anecdotal evidence of women with an actual or suspected gynaecological cancer (including ovarian cancer) having their primary surgery undertaken by gynaecologists or other general providers and then referred to the gynaecological oncologist. Subsequent ‘salvage’ surgery was reported as being more complex as a result of the earlier surgery. Anecdotal evidence indicates that this may occur in up to 10% of all women with gynaecological cancers. As a result there is a need to:
  - understand and quantify the extent of this problem
  - continue to emphasise the referral criteria for women with actual or suspected gynaecological cancer
  - develop and promote clear guidance for the surgical management of women in whom cancer is found unexpectedly
  - enhance timely communication and collaboration between different specialists.

Management of women with gynaecological cancer

The overarching goal for the National Framework as identified on page 11 is that:
- all women with a suspected (i.e. with symptoms indicative of a high risk of cancer) or actual gynaecological cancer have access to a comprehensive multidisciplinary team led by a gynaecological oncologist to provide high-quality management based on the best available evidence and tailored to women’s needs to achieve the best outcome for each woman.

In addition, close communication and collaboration is required between gynaecologists and gynaecological oncologists to ensure timely referral and appropriate management of all women including those whose symptoms fall outside of established referral criteria.

Follow-up care

A third area in which there could be a specific role for gynaecologists is in the follow-up management of women after definitive treatment.

There was clear evidence of this occurring in some situations around Australia, particularly for regional women and where the local gynaecological oncology services were stretched. However, this appeared to be relatively ad hoc based on individual women’s and service providers’ needs.

For gynaecologists (and all other providers) to offer follow-up care they need to be able to meet the requirements outlined in the service element “follow-up and survivorship” (see Service Delivery Element 3, Appendix F).

2.4 Radiation oncologists

Radiation oncologists play a crucial role within the multidisciplinary gynaecological cancer care team in providing radiotherapy either on its own or concurrently with chemotherapy.

Studies of radiotherapy optimal utilisation rates indicate an optimal utilisation rate for external radiotherapy of 35% and for brachytherapy of 28%. The optimal utilisation rates for external radiation for different gynaecological cancer types are:
- ovarian 4%
- endometrial 46% (with an optimal utilisation rate for brachytherapy of 43%)
- cervical 58% (with an optimal utilisation rate for brachytherapy of 49%)
- vulvar 34%
- vaginal 100%

Using these optimal utilisation rates, Table 6 (page 38) estimates the annual number of women requiring external radiotherapy or brachytherapy nationally and by state based on an average of 3994 new cases per annum (2001–2005).

Management of women with complex benign conditions

The number of women across Australia currently requiring complex surgery by gynaecological oncologists for benign conditions that could be treated by gynaecologists with more advanced surgical skills is unclear. Anecdotally it appears to be increasing with some indication that this may continue.

The long-term issue of the complex surgical management of women with non-malignant conditions may be resolved through the future RANZCOG workforce directions and a ‘specialist gynaecological surgery’ role (see box on page 32). However, there is a need to quantify the current impact of this burden on gynaecological oncologists and to consider mechanisms to address the burden in the shorter term.

One suggestion has been identifying and monitoring a small cohort of specific gynaecologists with an interest in and established level of surgical skill to manage at least some women requiring complex benign surgery. This may provide some relief to local gynaecological oncology services under stress. Clear criteria, structures and processes would need to be developed to ensure safe care for these women.
### Table 6: Estimated numbers of women currently requiring external radiotherapy or brachytherapy based on optimal utilisation rates

<table>
<thead>
<tr>
<th>State</th>
<th>Estimated number of women requiring external radiation per annum</th>
<th>Estimated number of women requiring brachytherapy per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>1398</td>
<td>1118</td>
</tr>
<tr>
<td>NSW (plus ACT)</td>
<td>480</td>
<td>384</td>
</tr>
<tr>
<td>Victoria</td>
<td>360</td>
<td>288</td>
</tr>
<tr>
<td>Queensland</td>
<td>265</td>
<td>212</td>
</tr>
<tr>
<td>Western Australia</td>
<td>132</td>
<td>106</td>
</tr>
<tr>
<td>South Australia (plus NT)</td>
<td>124</td>
<td>100</td>
</tr>
<tr>
<td>Tasmania</td>
<td>35</td>
<td>28</td>
</tr>
</tbody>
</table>

Assuming the optimal utilisation rates remain the same, of the 5228 women projected to develop a gynaecological cancer in 2015, the following increases are estimated:
- 1830 women requiring external radiotherapy—an increase of 432 women
- 1484 women requiring brachytherapy—an increase of 346 women.

### Current workforce practices and challenges

There is limited national data on actual practice to compare with the above estimated utilisation rates. Two studies based on 2003 NSW data reported:
- underutilisation of brachytherapy for endometrial cancer
- utilisation of brachytherapy for cervical cancer was approaching the optimal utilisation rate.

In consultations for this National Framework, stakeholders considered that there had been significant improvements in the utilisation of brachytherapy for women with endometrial cancer since 2003. Continuing improvements in radiotherapy utilisation and the projected increase in the numbers of women developing a gynaecological cancer will impact on future radiotherapy service capacity and workforce demands.

While the Faculty of Radiation Oncology in the Royal Australian and New Zealand College of Radiologists (FANZCR) is reported to be considering formal sub-specialisation in the future, the current training program is seen to provide radiation oncologists with the skills to provide radiotherapy to all cancer groups. However, given the increasing complexity of radiation therapy for different tumour groups, radiation oncologists tend to develop identified interests in one or more sub-specialty areas. In addition, relevant guidelines highlight the importance of women being treated by radiation oncologists with expertise in gynaecological cancer.

In a 2006 study (as reported in the earlier NCSC Workforce study), the following evidence was identified. Of the 242 radiation oncologists at that time:
- 87% were male across all age groups
- of the workforce aged under 45 years, 44% were women
- seven radiation oncologists identified themselves as sub-specialists in gynaecological cancer (sub-specialists being defined in that study as spending at least 50% of clinical practice in a specific sub-specialty)
- 20% of the overall workforce were aged 55 years and over, with just over 3% being over retirement age.

From the consultations, the provision of curative radiotherapy for women with a gynaecological cancer appears to be relatively centralised with treatment being provided within one to two treatment centres in most jurisdictions.

In NSW, radiotherapy is provided in several services, based within Sydney or in major regional centres. Some regional centres provide both external radiation and brachytherapy whereas others provide external radiation only, with brachytherapy being provided at a centralised service. This “shared care” model requires optimal communication and information flow between providers. Even with optimal information flow, a shared care model for women requiring external radiotherapy and brachytherapy was considered by many stakeholders as being sub-optimal and is not recommended for the future.

Specific issues identified through the consultation included:
- anecdotal evidence that some sub-specialists with significant expertise in gynaecological radiotherapy (including brachytherapy) are approaching retirement age and their retirement may lead to a significant loss of expertise locally and nationally
- the complexity of brachytherapy for gynaecological and other cancers requires an additional skill base and expertise that is built up over time
- while the numbers of women with gynaecological cancer treated with brachytherapy by one provider may be relatively small, they may also be treating other patients with brachytherapy that would build up their expertise
- high-volume centres (especially for brachytherapy) may be drawn on to provide additional skill development for radiation oncologists from other centres
- the potential for significant long-term physical and psychosocial morbidities for women following radiotherapy
- limited comparable evidence across “high-volume” and “low-volume” providers about mortality rates to guide directions in appropriate service provision
- competing training opportunities between trainee radiation oncologists and ensuring skill maintenance for practising radiation oncologists.

### The skills and requirements for a radiation oncologist

There is limited evidence of what might constitute a radiation oncologist with expertise in gynaecological cancers’ and whether an appropriate volume of women per radiation oncologist should be used to facilitate resource allocation and determine competencies. However, evidence in the management of cervical cancer indicates that there is a positive correlation between numbers of patients treated, brachytherapy applications and successful outcomes.

The UK guidelines into developing brachytherapy services for all patient groups provide directions of some relevance to Australian services including:
- gynaecological cancers are the most common type of cancer treated with brachytherapy accounting for 65% of all brachytherapy patients
- the number of women with a gynaecological cancer treated in a UK centre ranged from 13 to 174 per annum. Of the 40 centres reported:
  - 13% treated between 13 and 25 women
  - 28% treated 26–50 women
  - 36% treated 51–75 women
  - 10% treated 76–100 women
  - 13% treated 101–174 women
- following specialty certification, trainees and newly appointed consultants wishing to develop a sub-specialist interest in brachytherapy should receive fellowship support to attend larger centres (with a patient volume of at least 100 cases) for 6 to 12 months
- the UK standards for brachytherapy recommend that:
  - the minimum total brachytherapy case load per service should be more than 50 patients per year (all patient groups)
  - the service should be supported by at least two radiation oncologists
  - there should be access to surgical oncology expertise for multidisciplinary patient assessment and treatment
  - the minimum number of intra-uterine applicator insertions should be 10 per centre per year with each radiation oncologist attending more than five insertions and dosimetry reviews each year
  - annual audit should be undertaken documenting activity within each UK service and by clinician to demonstrate compliance with the standards.
While these UK standards provide a useful framework, Australian stakeholders indicated that the minimum volume standards have not been based on evidence of patient outcomes. Within Australia, some research has been undertaken that examined the technical indicators for radiotherapy and brachytherapy with 10 cases per centre per year being seen as the lower cut-off point to provide quality care. This study based on 2003 data has not considered volume and outcomes, including quality of life issues. A range of views were put forward and discussed to identify the core requirements for a radiation oncologist with an interest in gynaecological cancers. An agreed set of prerequisites for services and for radiation oncologists with ‘an interest in gynaecological cancers’ in different service contexts was identified. However, given limited evidence, these prerequisites for an optimal service may not be universally accepted.

Additional evidence is required potentially through a patterns of care study to inform the longer term requirements particularly in relation to the provision of brachytherapy including:

- volume requirements for services and/or individual service providers
- the safety and quality of shared care approaches to the provision of external radiotherapy and brachytherapy.

Specific skills and requirements for ‘a radiation oncologist with expertise in gynaecological cancers’ and their associated services

For individual radiation oncologists:
- completion of all RANZCR requirements for membership of the Faculty of Radiation Oncology including relevant continuous medical education and professional development requirements including practice audits
- newly qualified radiation oncologists should work as a radiation oncology fellow within a high-volume gynaecological cancer radiation service for at least six months prior to taking up a role as a radiation oncologist with a sub-specialty interest in treating women with gynaecological cancers
- provision of treatment for a minimum of 10 women with intra-uterine brachytherapy per year to maintain skills and expertise to manage the diversity of treatment demands
- active participation in multidisciplinary treatment planning processes including that any required examinations of women under anaesthetic are undertaken in collaboration with gynaecological oncologists
- knowledge of and access to clinical trials
- a thorough understanding of the impact of a gynaecological cancer and its treatment on women—particularly its psychosexual impact, with skills and strategies in place to identify and respond to women’s general supportive care and psychosexual needs

- participation in relevant quality assurance activities at a service level.

For radiation oncology services:
- optimally each service treating women with gynaecological cancers to nominate two radiation oncologists who will provide radiation therapy including brachytherapy to the given population within the service
- women requiring external radiation therapy and brachytherapy are treated by the same service
- for smaller volume providers (and new providers) formal organisational arrangements or strategies should be in place to facilitate:
  - access to secondary consultation
  - referral pathways for complex cases if needed
  - adequate staffing coverage to meet routine and unexpected leave requirements.

2.5 Medical oncologists

Medical oncologists are involved in the provision of chemotherapy for women with gynaecological cancers. A recent study indicated the following optimal utilisation rates for chemotherapy:

- ovarian cancer 84%
- cervical cancer 51%
- endometrial cancer 20%.

Using these figures at least 1700 women are estimated to currently require chemotherapy for a gynaecological cancer each year, with nearly 1000 of these women having ovarian cancer. Based on the AHW projections and current utilisation rates, this figure will rise to over 2100 women requiring chemotherapy by 2015, of whom 1220 will have ovarian cancer.

Current practice and workforce issues

The AHW Medical Labour Force Survey 2007 reported that there were 281 medical oncologists in the workforce. This represented an 8% increase on the numbers of medical oncologists reported in the equivalent report for 2005. Key data from these AHW reports indicate that:

- 34% of all medical oncologists in 2007 were female
- in 2007, 54% were aged 44 years or younger

Table 7: Ratios of medical oncologists to population by jurisdiction

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Total population in March 2009</th>
<th>Number of medical oncologists 2007</th>
<th>Estimated ratio of medical oncologists to total population</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>21,779,000</td>
<td>281</td>
<td>1:77,500</td>
</tr>
<tr>
<td>NSW</td>
<td>7,076,000</td>
<td>49</td>
<td>1:144,417</td>
</tr>
<tr>
<td>Victoria</td>
<td>5,400,000</td>
<td>101</td>
<td>1:53,491</td>
</tr>
<tr>
<td>Queensland</td>
<td>4,380,000</td>
<td>50</td>
<td>1:87,607</td>
</tr>
<tr>
<td>Western Australia</td>
<td>2,220,000</td>
<td>14</td>
<td>1:130,838</td>
</tr>
<tr>
<td>South Australia (incl NT)</td>
<td>1,820,000</td>
<td>17</td>
<td>1:130,227</td>
</tr>
<tr>
<td>Tasmania</td>
<td>501,800</td>
<td>7</td>
<td>1:71,686</td>
</tr>
<tr>
<td>ACT</td>
<td>349,950</td>
<td>4</td>
<td>1:87,487</td>
</tr>
</tbody>
</table>

- of the total number of hours worked in 2007, 57% reported working more than 50 hours per week
- of the clinical hours per week, 27% indicated working more than 50 hours per week which is comparable with the 2005 data
- in spite of the increased number of medical oncologists in 2007, there was a small increase in the average number of clinical hours worked per week (40.1 hours compared with 39.6 hours in 2005) demonstrating increasing demand absorbing additional resources.

There was some variation in the numbers of medical oncologists by jurisdiction and the ratios of medical oncologists to the population (see Table 7). Based on these 2007 figures, NSW, Western Australia and South Australia have the most ‘stretched’ medical oncology workforce.

The 2009 Australian Medical Oncology Workforce Study highlighted the following points:

- 476 medical oncology positions working as 234 full-time equivalents
- an additional 28.6 EFT were vacant
- uneven distribution of medical oncologists with shortages in all jurisdictions but greater shortages in NSW and Queensland.
an optimal workload of 150–180 new patients per full-time equivalent medical oncologist per year was assumed to estimate future resource requirements.

There are several identified differences between the 2007 and 2009 studies including:

• the numbers of medical oncologists reported
• the states that may have the greatest gaps.

These differences may reflect the different methods used to collect the workforce data.

Based on the optimal chemotherapy workload identified in the 2009 study and the estimated current and future numbers of women with gynaecological cancers who require chemotherapy:

• nine to 12 full-time medical oncologists would be required nationally to manage the current numbers of women with gynaecological cancers per annum.

• an additional two to three will be required to manage the projected numbers by 2015.

However, given the relatively small number and spread of women with gynaecological cancers across Australia, there are only a few medical oncologists for whom gynaecological cancers would represent a substantial component of their workload.

From the consultation the following points were highlighted:

• given the changing treatment protocols for different cancers, there is a move towards medical oncologists developing specific ‘sub-specialty’ interests.

• medical oncologists in smaller or regional centres may have a more general workload of which women with gynaecological cancers will be a part.

• the chemotherapy drugs for gynaecological cancers are conventional drugs given to treat a range of cancers which means chemotherapy may be given closer to home.

• given workload demands, it can be more difficult for regional medical oncologists to keep up-to-date with all changing treatment modalities for a wide range of cancers.

• smaller or regional services may not be able to support women accessing clinical trials.

• a proportion of women with gynaecological cancers will have concurrent chemotherapy and radiotherapy and this requires close collaboration between providers and optimally co-location of the treatment modalities for ease of access for women.

• where medical oncology resources are very stretched, attendance at multidisciplinary treatment planning meetings may be difficult and require alternative processes.

The skills and requirements for medical oncologists

The box on page 42 outlines the agreed elements for ‘a medical oncologist with expertise in gynaecological cancers’ in different service contexts.

2.6 Pathologists

Pathologists play a pivotal role in the management of women with gynaecological cancers. The timely and full exchange of information between the operating gynaecological oncologist and the pathologist is an essential part of any good-quality service. In addition to providing a definitive diagnosis, pathologists provide information necessary for the staging of the cancer, evaluation of the adequacy of the surgical excision, determination of appropriate chemotherapy and/or radiation therapy and identification of important prognostic indicators.

This information is critical for treating clinicians to guide the optimal management of women with gynaecological cancers. In addition any retrospective review of different treatment protocols is only as valid as the accuracy of the initial pathological diagnosis and staging.

For many pathologists, their role related to gynaecological cancers is integrated into a broader service role and is impacted by significant broader workforce issues.

The following evidence or issues were identified for the provision of pathology services:

• There are significant workforce challenges with the 2008 workforce study identifying that 34% of anatomical pathologists were aged 55 years and over.

• A 2003 report on supply and requirements of the pathologist workforce in Australia identified that an additional 500 trainee pathologist positions were required. However, by 2009, only 140.5 places had been funded.

• RCPA’s recently released workload study considers the impact of workload on anatomical pathologists on quality and safety.

Key findings from this study included:

– 68% of pathologists surveyed usually worked full-time (at least 40 hours per week) and 32% usually worked part-time.

– On average full-time pathologists were working 48 hours per week, while part-time pathologists worked 34.7 hours per week.

– 77% of pathologists surveyed reported that increased workloads over the past few years had impacted on their ability to undertake quality assurance activities.

– Those pathologists who reported working at above capacity were more likely to report that they were too busy to undertake their usual quality assurance activities.

– Different pathology workforce approaches may occur in different settings with each approach having strengths and limitations:

– In some laboratories, pathologists may be specifically designated to undertake all gynaecological cancer pathology.

– In other laboratories, gynaecological pathology work may be undertaken by all pathologists (a more generalist role) although one to two may have a role in reviewing slides for presentation at multidisciplinary meetings.

– Structured pathology reporting with standardised definitions for each component has been shown to significantly enhance the completeness and quality of the data provided to clinicians.

Specific skills and requirements for a medical oncologist with expertise in gynaecological cancers and their associated services

For individual medical oncologists:

• completion of the relevant requirements for membership of the Royal Australian College of Physicians and MOGA including relevant continuous medical education and professional development requirements.

• active members of the multidisciplinary team planning processes and/or other strategies to optimise multidisciplinary care.

• have knowledge of and access to clinical trials.

• small-volume providers or regional providers should have access to:

  – local or centralised multidisciplinary team planning processes and protocols
  – secondary consultation if needed
  – referral pathways to facilitate women’s access to appropriate clinical trials

• understanding of the impact of gynaecological cancers and their treatment on women and the ability to identify and respond to women’s supportive care and psychosocial needs appropriately.

• participation in relevant quality assurance activities at a service level.

For medical oncology services:

• each service treating significant numbers of women with gynaecological cancers should have at least one medical oncologist who will provide chemotherapy to all or the majority of the given population within the service. The pro-rata EFT required should be based on the optimal figure of 150–180 new chemotherapy patients per 1 EFT medical oncologist.

• at least one other medical oncologist should be available with enough expertise to provide back-up to and succession planning for the main provider.

• for smaller volume providers, formal organisational arrangements or strategies should be in place to facilitate:

  – access to secondary consultation
  – referral pathways for complex cases if needed

  – ensuring adequate staffing coverage to meet routine and unexpected leave requirements.

[ BACK TO CONTENTS ]
As a result RCPA, with Cancer Australia and the Department of Health and Ageing, is currently developing structured pathology reporting in gynaecological cancers to provide further guidance to pathologists.

- Pathologists connected with some specialist centres report being overburdened with local gynaecological cancer service demand, other demands within their service and the demand for reviews of external pathology which is usually unfunded.
- Where pathology slides are forwarded to a tertiary setting for review, delays in undertaking the review impact on the subsequent management of women.
- Preparation of pathology slides for multidisciplinary meetings, for both pre-operative assessment and post-operative review, place significant additional demands on pathologists; this demand is not adequately funded through the current funding mechanisms including Medicare items for multidisciplinary reviews.

Other providers are constrained from being active participants in multidisciplinary meetings by competing work priorities, limited interest and/or reluctance to contribute to local or centralised multidisciplinary treatment planning.

- The current lack of a payment mechanism for second opinions in pathology inhibits the ability to adequately resource case reviews.

The following box identifies the agreed requirements for a pathologist with expertise in gynaecological cancers and the associated pathology services.

### Specific skills and requirements for a pathologist with expertise in gynaecological cancers and their associated services

**For individual pathologists:**

- completion of all the relevant requirements for membership of RCPA including relevant continuous medical education and professional development requirements
- have additional knowledge and expertise in gynaecological cancer pathology
- actively use a structured approach to reporting gynaecological cancer pathology
- be active members of the local gynaecological cancer multidisciplinary team
- are encouraged to actively participate in local or international specific interest groups (e.g. ASCOIP, ISSG and IGCS).

**For pathology services:**

- at a minimum, each pathology service needs to identify a core group of pathologists with knowledge and expertise in reporting gynaecological cancer pathology—within a large laboratory, this should be greater than two pathologists. These pathologists would be active members of their local gynaecological cancer multidisciplinary team
- services and systems are established and resourced to:
  - ensure review of all relevant slides, histological and cytological, prior to surgery
  - ensure prompt review of slides sent from other services and timely communication of results to meet the needs of the treating clinician or multidisciplinary meeting
  - encouragement of one-on-one discussion between the pathologist and the gynaecological oncologist to facilitate decision-making and learning
  - organisational structures and processes between networks of services are established to support pathology review, professional development and quality assurance across large and smaller services
  - payment mechanisms are developed to ensure review work is adequately resourced
  - participation in quality review processes.

### Specific skills and expertise for radiologists with an interest in gynaecological cancers

**For Radiologists**

A number of issues have been highlighted that may impact on radiology services for women with gynaecological cancers including:

- the broader workforce issues and current and future shortages
- increasing sub-speciality interests within radiology with other sub-specialties being seen as more attractive
- more limited interest in women’s imaging
- limited MBS rebates for some imaging modalities such as magnetic resonance imaging
- variable use of imaging in assessment, management and follow-up — this may occur because of lack of evidence of the benefit or lack of MBS funding
- lack of feedback to radiologists from other treating clinicians, e.g. gynaecological oncologists, about the adequacy of radiology in enhancing diagnosis or ongoing assessment.

The following box identifies the skills or expertise for radiologists with an interest in gynaecological cancers.

### Specific skills and requirements for radiologists with an interest in gynaecological cancers

- Completion of the relevant requirements for membership of RANZCR including relevant continuous medical education and professional development requirements.
- Relevant expertise in women’s imaging and/or general oncology imaging.
- Regular experience in pelvic ultrasound for all gynaecological conditions.
- Participation in multidisciplinary review meetings and/or one-on-one consultation with the referring clinician.
- The availability of secondary consultation and mentoring for less experienced radiologists.
- The provision of feedback on the quality of imaging and reporting.
- Participation in quality review processes.

### 2.8 Specialist and generalist nursing roles

‘When you are in hospital you feel so vulnerable and frightened that it is so important that the nursing staff are knowledgeable, kind and caring.’

The workforce issues for specialist and generalist nurses working with women with gynaecological cancers are considered within the context of other recent nursing initiatives.

**The National Professional Development Framework for Cancer Nursing**

The 2009 EdCan Framework (and the accompanying teaching and learning resources) takes a population-based approach that enables nurses’ professional development needs to be considered in parallel to the needs of the population affected by cancer. It applies the national nursing competency standards, developed by the Australian Nursing and Midwifery Council (ANMC), to define the scope of practice for cancer control for enrolled nurses, registered nurses and nurse practitioners.18

The EdCan Framework also emphasises that within each nursing group, nurses may function at varying levels of competence from the beginning level through to advanced levels. The more advanced levels result from experience and additional professional development and enable more effective integration of theory, practice and experience along with increasing degrees of autonomy in judgements and intervention.19 The roles of nurses in gynaecological cancer care should be considered within the context of the EdCan Framework and broader cancer nursing workforce initiatives.

**The role of the nurse practitioner**

Across Australia there is increasing emphasis on the development of nurse practitioner roles in a range of service contexts. Within gynaecological cancer care, there is the potential to explore the role of nurse practitioners in:

- the management of women with abnormal Pap test results — this role has been successfully established in New Zealand for a number of years
PART 2
Workforce development

- follow-up care for women after gynaecological cancer treatment
- other roles identified through role redesign activities that optimise the use of advanced nursing skills.

The future gynaecological cancer nursing workforce

The NGSIC Workforce report(6) identified the following factors about the nursing workforce including:

- oncology nursing represents only a small component of the care delivered by the nursing workforce overall
- there has been a significant increase in the number of registered nurses who identified oncology as their principal area of work
- most oncology nurses work in metropolitan services reflecting the location of major cancer services; only 13% of nurses who identify oncology as their main area of clinical work, work within inner or outer regional areas
- it is not possible to identify nurses whose main area of work is gynaecological cancers from genitourinary nursing workforce statistics.

The consultation process for this National Framework identified significant diversity in nursing roles for women with gynaecological cancers including nurses in:

- community settings in which women with gynaecological cancers may be a very small proportion of their caseload. In some community settings the predominant focus will be on health promotion and cancer prevention and screening, with evidence of women’s health nurses providing an important role in cervical screening for under-screened women. Community providers may also be involved in supporting women with an advanced gynaecological cancer requiring symptom management and palliative care support.
- general acute care service settings, e.g. general medical and surgical units (public or private) for whom women with gynaecological cancers may also be a small proportion of their practice. This includes nurses with specific specialist skills such as sternal therapy
- specialist cancer settings, e.g. day oncology services where gynaecological cancers may be a small part of a mixed cancer patient load
- specialist gynaecological cancer settings, usually high-volume centres, in which women with gynaecological cancers are all or a significant proportion of the patient population

- designated specialist nursing roles with expertise in gynaecological cancers (gynaecological cancer nurse consultant or coordinator).
- these supervisory roles may transact the care pathway within or across services and sectors or provide in-depth specialist care within a specific pathway point. These nurses positioned within specialist centres play a significant role in:
  - assessing women’s needs, responding to needs and ensuring appropriate referral
  - providing information, support and specialist nursing skills to women
  - facilitating coordinated care within and across services and sectors
  - professional development and mentoring for general nursing staff
  - strategic service planning and involvement in research and national and international networking.

These roles align well with evidence that the optimal benefit of any specialist nursing role is gained when roles are well defined to deliver aspects of clinical care, patient information and education, effective care coordination and professional development.

A number of issues related to current nursing practice were identified including:

- limited gynaecological cancer expertise of nurses working in general acute care service settings
- a need to improve nurses’ understanding of the whole gynaecological cancer journey to assist women prepare for the next steps, e.g. radiotherapy or brachytherapy
- unless proactively addressed through appropriate guidance, nursing networks and educational programs, the disaggregation of designated gynaecological oncology inpatient units may potentially lead to a loss of specialist nursing knowledge
- in the absence or loss of a designated specialist gynaecological cancer unit, the need for specialist nurse consultant/coordinator roles is greater both to facilitate women’s care through the system but also to act in a mentoring role for less experienced staff
- concern that without clear role boundaries:
  - there is an over-dependency on specialist nurse consultant/coordinator roles to fill a range of service gaps resulting in excess burden on the role
  - limited succession planning

- limited resources to support nurses to undertake further professional development, support nurse practitioner roles and/or to undertake nursing research.

To address these issues, nurses working in different multidisciplinary settings need a range of competencies to provide the right care for women with or at risk of a gynaecological cancer, based on women’s needs, the service context and the nursing role.

Table 8: Suggested competency levels for nurses caring for women with gynaecological cancers in different service contexts

<table>
<thead>
<tr>
<th>Service context</th>
<th>Population served</th>
<th>Suggested range of additional nursing competencies required within the service context</th>
</tr>
</thead>
<tbody>
<tr>
<td>General service, e.g. community setting or general medical/surgical unit within metropolitan or regional services</td>
<td>People with a wide range of different cancers with some patients being women with gynaecological cancers.</td>
<td>All registered or enrolled nurses have achieved the core competencies for registered or enrolled nurses applied to cancer control. Depending on the service context the focus may include the following:</td>
</tr>
</tbody>
</table>
| Specialist gynaecological cancer setting, e.g. day oncology unit, palliative care, general radiotherapy service | In community settings: women with gynaecological cancers are seen very occasionally with the predominant population being well women. In other settings, women with gynaecological cancers are a small but regular component of the service population. | - the provision of information about health promotion and screening practices
- an understanding of cancer and its impact on people and their families
- assessment of need and the provision of care or referral relevant to the service context.

In settings regularly caring for women with gynaecological cancers, at least one registered nurse will demonstrate the application of these core capabilities at a more advanced level and hold portfolio responsibility for supporting the care of women with gynaecological cancers and communicating with local multidisciplinary gynaecological cancer care teams.

Access to specialist cancer nurses with specific competencies in gynaecological cancers relevant to the service’s specific pathway point. This expertise may be available on site to support direct care or through cross-organisational arrangements for secondary consultation.

Specialist gynaecological cancer setting, e.g. dedicated gynaecological cancer unit | High-volume service where all or a significant proportion of the service population are women with gynaecological cancers. | All registered or enrolled nurses can demonstrate the core competencies for registered or enrolled nurses as applied to cancer control. A proportion of these nurses will be able to demonstrate these core capabilities at an advanced level relevant to the service setting.

Senior nurses will be working towards or can demonstrate the core capabilities of the specialist cancer nurse role relevant to the service context and will include:
- a good understanding of gynaecological cancers and their impact on women
- the ability to assess (including a risk assessment) and respond to the specific needs of women (including supportive care and psychosocial issues) and provide care within their scope of practice or refer to other providers.

Access to specialist cancer nurses through the service site or linked services, working at an advanced level with specific competencies in working with women with gynaecological cancers.

At a minimum, registered or enrolled nurses can demonstrate the core competencies for registered or enrolled nurses as applied to cancer control, with a proportion demonstrating these core capabilities at an advanced level.

Some nurses will be working towards or can demonstrate the core capabilities of the specialist cancer nurse relative to the service context which includes:
- a sound understanding of gynaecological cancers and their impact on women
- the ability to assess and respond to the specific needs of women with gynaecological cancers and provide coordinated care within their scope of practice.

Access to specialist cancer nurses within the service unit working at an advanced level with specific competencies in working with women with gynaecological cancers.

At a minimum, all roles require the incumbent to be working as a specialist cancer nurse with advanced competencies for working with women with gynaecological cancers; the advanced capabilities will be contingent on the service context.

In some contexts, incumbents may be working towards or have achieved the competency standards to take up a nurse practitioner role.

Well women’s health nurses/nurse practitioners providing cervical screening have the competencies required for credentialed Pap test providers.
Strategies for developing a strong network of nurses with appropriate levels of skills and competencies include:

- building on educational opportunities and informational resources including:
  - accessing current and future modules of the EdCan online nursing educational programs to address specific aspects of gynaecological cancer care
  - linking with related professional programs to enhance general and specialist nursing skills in managing women with gynaecological cancer including short courses to strengthen gynaecological cancer knowledge for generalist nurses
- accessing the NCCG’s suite of gynaecological cancer information resources

- ensuring that all specialist centres have access to a specialist cancer nursing role with expertise in gynaecological cancers to optimise care of women, provide educational and mentoring support for internal and external nursing staff and be an active contributor to service planning and relevant nursing research activities

- developing formal organisational networks (see page 27) so that nursing expertise in specialist centres can be drawn on to provide:
  - advice to generalist nursing providers in other services
  - peer support for other specialist cancer nurses working with women with gynaecological cancers in smaller or more isolated environments

- utilising current advanced nursing practice policy initiatives at a jurisdictional level along with other support to trial advanced nursing practice roles that will enhance care for women, e.g. in providing well women’s services for under-screened women or providing follow-up care for women on completion of their cancer treatment.

2.9 Supportive care providers

I found that I was on my own and only when I hit rock bottom was I taken aside and referred to get some psychological help to first explain what was happening. And from there I had to work it out on my own how I could best manage my personal situation. I learnt the hard way, in silence, because I didn’t really know what to expect and who to turn to.’

Supportive care covers a wide range of physical, social, psychological, spiritual and information support needs which may be addressed by different generalist and specialist disciplines. In addition the concept of supportive care (extending from the concepts of psychosocial care or psycho-oncology) is an evolving one and its current adoption at a jurisdictional, professional and service level is variable.

As a core component of all cancer care and one of the eight service delivery elements within this National Framework (see Service Delivery Element 6, Appendix F), the many components of supportive care are provided by the general cancer workforce, general service providers and specific specialist providers. This links in with the tiered approach to supportive care (see Figure 4) that is being increasingly adopted nationally and internationally.77 This tiered approach addresses the diversity of supportive care with its five domains of need and the range of different interventions and skills required to respond to different levels of need.

Within gynaecological cancer care, supportive care may be provided by:

- the general gynaecological cancer care team who will assess and respond to a range of needs across the dimensions of supportive care through their practice
- specialist psychosocial care providers such as social workers, psychologists, sexual counsellors who may work with women with identified needs. The scope of their work may include:
  - women with gynaecological cancers only
  - broader groups of cancer patients and their families
  - general mixed populations within the community or acute care services
- other specialist clinical providers who may address specific supportive care needs that are identified including:
  - medical specialists such as psychiatrists and fertility and menopause specialists
  - allied health providers such as dietitians, occupational therapists, physiotherapists and lymphoedema practitioners
  - specialist palliative care providers (see page 55)
- GPs are also seen as playing a role in supportive care (see page 55).

There is overlap in the skills between different disciplines that may be involved in providing supportive care at a service level.

Figure 4: The tiered approach to providing supportive care

<table>
<thead>
<tr>
<th>ALL WOMEN WITH GYNAECOLOGICAL CANCERS</th>
<th>FEW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good communication and information</td>
<td>Intensive or comprehensive care for acute or complex and multifactorial psychological, physical or social problems.</td>
</tr>
<tr>
<td>Respectful and dignity-conserving care</td>
<td></td>
</tr>
<tr>
<td>Screening for risk and current needs.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MANY WOMEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link with self-help and peer support.</td>
</tr>
<tr>
<td>Access to practical assistance.</td>
</tr>
<tr>
<td>Participate in psycho-educational groups</td>
</tr>
<tr>
<td>Behavioural interventions, e.g. relaxation.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist care for identified issues, e.g. depression, anxiety, relationship problems and more complex physical, social and psychosocial issues.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FEW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensive or comprehensive care for acute or complex and multifactorial psychological, physical or social problems.</td>
</tr>
</tbody>
</table>

Given that the concept and practice of supportive care in cancer is evolving and gradually extending, the guidance in this National Framework should be seen as a starting point for identifying the workforce resources and skills required to meet the needs of women with gynaecological cancers. This section:

- addresses the supportive care skills of the generalist workforce
- focuses more specifically on access to specialist psychosocial and psychosexual skills
- broadly addresses the additional skills required by other clinical specialists.
Current practices and workforce issues

In addition to the general workforce involved in providing supportive care as part of their cancer care role, there were three core supportive care roles identified within current specialist gynaecological cancer services, two of which have a strong psychosocial focus:

- gynaecological cancer nurse consultant/co-ordinator
- social worker
- psychologist.

The current EFT workforce for these three roles in 13 identified specialist gynaecological cancer services (specialist centres) across Australia is summarised in Table 9. Eleven of the services have a nurse consultant role (mostly 1 EFT) to meet variable levels of service demand. While a detailed analysis of this role has not been undertaken, there is variability in the roles and only one component of the nurse consultant role may be directly related to supportive care. Care should also be taken to ensure that the responsibility of supportive care is not seen as the prime responsibility of the nurse consultant role, which may result in over-burdening. Within the specialist centres, there is significant variance in access to social work and psychology services with some being relatively well resourced, whereas others have few dedicated social work or psychology resources and/or limited access to more general cancer or general supportive care services. This variance may reflect the broader service context in which the individual specialist centres are located. It may also reflect more limited general access to and significant service gaps in supportive care providers across all health services and sectors, with stakeholders indicating:

- significant contraction of all allied health resources within public health services
- access may be even more constrained within the ambulatory care setting when cancer patients are still accessing acute treatment services
- limited access to supportive care providers in the private sector (i.e., private hospitals).

Specific issues identified included:

- anecdotal evidence from services offering a visiting specialist model indicates more limited attention being paid to women’s supportive care needs
- limited evidence of formal supportive care screening being undertaken routinely using a validated screening tool; this in part is due to continuing concerns about the utility and efficacy of screening and more limited evidence of how screening can be effectively introduced into routine practice
- working with women with gynaecological cancers was perceived by some specialist providers to have a level of intensity not experienced with other cancer patients
- different supportive care providers have overlapping roles signalling the need for collaboration across disciplines
- there was limited access to psychosexual counsellors; in some services, these issues were addressed by various providers including the nurse consultant, social worker or psychologist depending on their skill base

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of new patients per annum</th>
<th>Nurse consultant/co-ordinator</th>
<th>Dedicated social worker</th>
<th>Psychologist</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not known</td>
<td>1 EFT</td>
<td>As needed</td>
<td>Nil</td>
</tr>
<tr>
<td>2</td>
<td>98</td>
<td>1 EFT</td>
<td>0.1 EFT</td>
<td>0.5 EFT</td>
</tr>
<tr>
<td>3</td>
<td>138</td>
<td>1 EFT</td>
<td>0.5 EFT</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>155</td>
<td>1 EFT</td>
<td>Part-time</td>
<td>As needed</td>
</tr>
<tr>
<td>5</td>
<td>99</td>
<td>1 EFT</td>
<td>0.4 EFT</td>
<td>As needed</td>
</tr>
<tr>
<td>6</td>
<td>400</td>
<td>1 EFT</td>
<td>1 EFT</td>
<td>Part-time</td>
</tr>
<tr>
<td>7</td>
<td>250</td>
<td>1 EFT</td>
<td>0.5 EFT</td>
<td>0.8 EFT</td>
</tr>
<tr>
<td>8</td>
<td>185</td>
<td>1 EFT</td>
<td>1 EFT</td>
<td>As needed</td>
</tr>
<tr>
<td>9</td>
<td>Not known</td>
<td>1 EFT</td>
<td>1 EFT</td>
<td>1 EFT</td>
</tr>
<tr>
<td>10</td>
<td>163</td>
<td>Nil</td>
<td>As needed</td>
<td>As needed</td>
</tr>
<tr>
<td>11</td>
<td>191</td>
<td>1 EFT</td>
<td>1 EFT</td>
<td>0.8 EFT</td>
</tr>
<tr>
<td>12</td>
<td>220</td>
<td>0.9 EFT</td>
<td>As needed</td>
<td>As needed</td>
</tr>
<tr>
<td>13†</td>
<td>276</td>
<td>Nil</td>
<td>1 EFT</td>
<td>1 EFT</td>
</tr>
</tbody>
</table>

1. Service mapping data was not completed from this service but this specific data was collected informally from the relevant service providers.

The generalist supportive care workforce

The tiered approach requires that the capacity of all the multidisciplinary team members (including medical and nursing) be strengthened to identify and respond appropriately to women’s supportive care needs. Within Victoria, work has been undertaken to develop a framework for professional competency in the provision of supportive care as part of the implementation of the Victorian Supportive Care Policy.

Key features of this framework include:

- translating the different levels of need of the cancer population to the competencies required of all, many, some few health service providers
- specific competencies to address the requirements that all and many health professionals need to identify (including through routine screening) and address supportive care needs at the levels of an individual patient, organisation or community
- the competencies needed by all or many providers within a multidisciplinary team focus on:
  - communication skills
  - provision of patient information and education
  - facilitating patients’ self-management skills
  - knowledge of internal and external supportive care resources and providers
  - skills to facilitate referral.

This Victorian supportive care framework is currently being finalised and will be implemented and evaluated over the next one to two years. These activities will complement the following supportive care requirements for general service providers working with women with gynaecological cancers outlined within this National Framework.
**Specific supportive care requirements of general service providers including medical and nursing staff**

- An understanding of the impact of gynaecological cancers and their treatment on women and their families and those factors that might increase women’s psychosocial distress.
- Skills to:
  - screen (or trial screening) for risk of distress and supportive care/psychosexual needs
  - provide an initial response and facilitate appropriate referral as needed
  - contribute to the evaluation of the benefit and outcomes of supportive care screening.
- Good communication skills appropriate to their role in providing information and support to women.
- Ability to sensitively address the needs of specific groups of women including Aboriginal and Torres Strait Islander women, women from CALD communities, women with a disability, mental health concerns or experience of sexual abuse.
- Higher level skills to identify and respond to physical symptoms such as pain and fatigue appropriate to their discipline and scope of practice.
- Ability to work collaboratively with women and other providers to respond to women’s needs.
- Knowledge of internal and external supportive care resources to facilitate referral.
- Access to specialist supportive care providers for secondary consultation.

**Table 10**: The specific skills and requirements for specialist psychosocial supportive care providers working within different service contexts.

<table>
<thead>
<tr>
<th>Specialist psychosocial/supportive care providers who regularly work with women with gynaecological cancers</th>
<th>Specialist psychosocial/supportive care providers who occasionally work with women with gynaecological cancers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet the relevant requirements of their professional discipline</td>
<td>Meet the relevant requirements of their professional discipline</td>
</tr>
<tr>
<td>Significant work experience within their discipline and ability to work at a senior level</td>
<td>Understanding of the impact of cancer on individuals and families and those factors that might increase psychosocial distress</td>
</tr>
<tr>
<td>Understanding of the impact of gynaecological cancers and their treatment on women and their families and factors that increase women’s psychosocial distress</td>
<td>Access to information on gynaecological cancers and their treatment to understand any specific impact on individual women and their families</td>
</tr>
<tr>
<td>Experience of working with family units and children under stress, as well as with individuals and groups</td>
<td>Ability and confidence to use and adapt their broad professional skills to assess and respond to the specific needs of individual women with cancer and their families</td>
</tr>
<tr>
<td>Able to undertake a comprehensive assessment and:</td>
<td>Skills in working with people experiencing loss and grief</td>
</tr>
<tr>
<td>– implement psychosocial and psychosexual interventions appropriate to their professional skill base and sensitive to women’s individual needs including cultural perspectives, mental health issues and any past sexual assault experiences</td>
<td>Access to secondary consultation through linkages with colleagues who work regularly with women with gynaecological cancer and/or general cancer populations</td>
</tr>
<tr>
<td>– identify issues that need to be addressed by other members of the multidisciplinary team</td>
<td></td>
</tr>
<tr>
<td>Be part of the multidisciplinary team and work collaboratively with other generalist and specialist supportive care providers</td>
<td></td>
</tr>
<tr>
<td>Have sound knowledge of internal and external supportive care resources to facilitate referral and community linkage</td>
<td></td>
</tr>
</tbody>
</table>
| Be able to act as a mentor to other members of the multidisciplinary team and be a resource for secondary consultation for other internal or external general and specialist supportive care providers | Other supportive care providers

Other providers who have contact with women with gynaecological cancers and address specific supportive care needs cover a wide range of clinical disciplines including allied health providers (e.g. dietitians, occupational therapists, physiotherapists, lymphoedema practitioners and pastoral care providers) and medical specialists (e.g. psychiatrists and fertility and menopause specialists). Significant resource gaps have been identified in these service provider groups and their capacity to address the needs of their broader service population. Strategies to address these broader resource gaps should include the needs of women with gynaecological cancers and other cancer types.
The following box identifies the base skills that are required by other service providers that will address different dimensions of supportive care needs through their discipline specific roles.

Specific supportive care skills and requirements for other members of the multidisciplinary team

- Understand the impact of cancer (including gynaecological cancers) on individuals and the implications for assessment and management within their agreed scope of practice.
- Ability to identify or screen for women’s broader supportive care needs, provide an initial response and facilitate appropriate referral to other supportive care providers.
- Ability to work collaboratively with women and the multidisciplinary team to respond to women’s needs.
- Knowledge of internal and external supportive care resources to facilitate referral.
- Ability to provide and/or access secondary consultation.

• Identifies specific team members who access higher level skill development to enable them to provide a higher level of psychosexual counselling within their role.

2.10 General practitioners

‘I have experienced complex health issues over time … each day the list seems to grow. It’s only since the help of my GP that the connection has been made between my cancer history and my symptoms … that I have found my way back into the health system.’

GPs are an important member of the multidisciplinary team involved in the management and care of women throughout the gynaecological cancer pathway from prevention to long-term survival & palliation. There are, however, significant challenges for GPs in this role given the relatively small numbers of women who develop a gynaecological cancer and the large number of GPs across Australia.

GPs play a crucial role in:
- HPV vaccinations for young women
- cervical cancer screening (90% of all Pap tests are performed by GPs) and the management and referral of women with screen-detected abnormalities
- assessing women who present with symptoms that indicate a potential cancer and referring appropriately
- supporting women with a gynaecological cancer and their families throughout the pathway, depending on the individual woman’s circumstances and needs.

GPs require skills and knowledge that build on their broader skill base to support women accessing relevant prevention and screening programs as well as these women with a suspected or confirmed diagnosis of a gynaecological cancer. A range of information and educational resources is available or currently being developed to support GPs including those available through the:
- National Cervical Screening Program and the relevant jurisdictional programs
- National HPV vaccination program register that enables GPs to check the vaccination status of their patients
- National Breast and Ovarian Cancer Centre, including information on assessing symptoms that may indicate ovarian cancer and advice about familial aspects of cancer

- Cancer Learning website that has access to a range of resources and materials including the online GP learning module, Managing gynaecological malignancies in general practice (funded by the NGCO)22
- Royal Australian College of General Practitioners including guidelines for preventive activities in general practice
- Program of Experience in the Palliative Approach (PEPA), a Commonwealth-funded program that is coordinated through the individual jurisdictions
- NGCO information resources on:— the different gynaecological cancers for women and general service providers— investigation of abnormal vaginal bleeding in pre-, peri- and post-menopausal women which may indicate endometrial cancer.

New resources or strategies that would be beneficial to support GPs include:
- simple generic treatment pathways or other information or educational resources that:
  - demonstrate different approaches to managing women with a gynaecological cancer
  - provide listings of common short- and long-term effects of different treatment modalities and management strategies
  - provide guidance about responding to the supportive care needs of women through the gynaecological cancer pathway including lists of relevant community-based resources available to support women
- provision of a copy of a woman’s individualised treatment plan at the time of diagnosis, completion of treatment and at other times when her clinical status changes, outlining specific treatment received, outlook, possible side-effects and key contacts
- local strategies that would enable the GP to link in with the multidisciplinary treatment planning meetings.

2.11 Specialist and non-specialist palliative care providers

Addressing palliative care workforce issues to respond to the needs of women with advanced gynaecological cancer must be undertaken with consideration of broader palliative care strategic directions and workforce challenges.

Palliative care service development

There is increasing understanding of the needs of all people living with a life-limiting illness and their families to have access to appropriate care and support to meet their physical, social, practical, emotional and spiritual needs. This includes access to specialist palliative care medicine, nursing, allied health and bereavement services. The family and the community also play an important role in supporting those with life-limiting conditions.24 Not all people who are dying need access to specialist palliative care services. As a result a needs-based population approach is advocated for sustainable palliative care service development across Australia.25
A recent report has highlighted significant issues in accessing specialist palliative care services when needed particularly in regional Australia including:

- Australia has about half the palliative care medicine specialists it needs
- Data identifies that the number of specialist palliative medicine specialists outside of the greater Sydney metropolitan area is about one per 100,000 of the state average
- Current staff shortages result in system-wide issues such as an inability for staff to take leave, limited availability of locums and lack of inter-professional support.

In addition, general workforce shortages including general practitioners and nursing have a flow-on effect that impacts on people living with a life-limiting condition gaining access to all levels of palliative care.

Finally, in 2009 the National Health and Hospitals Reform Commission identified the following four specific recommendations on caring for people at the end of life:
- Building the capacity and competence of the primary healthcare services to provide generalist palliative care support for dying patients
- Strengthening access to specialist palliative care services for all relevant patients across a range of settings
- Additional investment in specialist palliative care services directed towards supporting those living at home in the community
- Support for stronger implementation of advance care planning for those in residential aged care services and then extending this to other relevant groups in the population.

Supporting women with an advanced gynaecological cancer

Nationally just over 1562 women died of a gynaecological cancer in 2005 which represents about 1% of all Australian deaths and 4% of all cancer deaths. However, evidence from stakeholders indicated that:

- Women with an advanced gynaecological cancer are more likely to have complex needs that require early referral and access to specialist palliative care expertise for assessment, care planning and management with ongoing review as required
- Women with potentially curative cancer may have significant complex symptoms that would benefit from specialist palliative care input

Specific skills and requirements for non-specialist (generalist) palliative care providers

For individual service providers, dependent on their role:
- Ability to assess and manage common physical, psychological, social, practical and/or spiritual symptoms/needs of the woman and the needs of her family within her unique social and cultural context and to refer appropriately
- Excellent communication skills to identify information needs and facilitate optimal decision-making and advance care planning for women
- Particular skills in care planning including liaison with the treating specialists and specialist palliative care providers to determine by whom and where care should be provided and what support will be needed for the woman and her family
- Excellent communication with and referral to other providers including general practitioners and specialist palliative care providers (inpatient and community-based services).

For non-specialist services including specialist gynaecological cancer services:
- Ensuring that palliative medicine and/or nursing specialists are a core part of the multidisciplinary team and that policies and processes are in place to facilitate referral and consultation
- Ensuring that the non-specialist palliative care workforce has the skills and capacity in the palliative approach and advance care planning to respond to women’s needs, coordinate care and link with community-based services
2.12 Aboriginal health workers

Aboriginal health workers may work in a wide variety of services and settings including:
- Aboriginal and community services
- community health services
- acute care services
- palliative care development.

Depending on their nature, these services and the Aboriginal health workers may be based in large services in metropolitan and regional centres or much smaller services in rural, remote and very remote parts of Australia.

In relationship to cancer, Aboriginal health and community workers may be involved in:
- the provision of health promotion, education and prevention programs or linking women with these programs
- cancer screening programs as part of ‘women’s business’
- supporting Aboriginal and Torres Strait Islander people accessing acute care services which may involve intra- or interstate travel
- liaison between acute health services and general and Aboriginal-specific community services
- supporting community members and their families when palliative care is required including supporting people to return to country to die at home if that is their preference.

Any work to address the required skills of Aboriginal health and community workers involved in cancer care/gynaecological cancer care should be considered within the context of related initiatives including:
- current government initiatives to improve the management of complex and chronic diseases (including cancer) in Aboriginal and Torres Strait Islander communities particularly in remote and very remote areas
- the broader agenda of strengthening cancer awareness and services and skills of all Aboriginal health and community workers to be able to:
  - actively promote cancer prevention and screening messages appropriately within wider health promotion programs (this includes initiatives being undertaken through the National Cervical Screening Program and Breast Screen Australia)
  - respond to the needs of their community members affected by cancer
- specific programs to strengthen the cancer knowledge and skill base of Aboriginal health and community workers including cancer care programs developed by some of the state Cancer Councils (e.g. Queensland and Western Australia) and the recent PEPA program to strengthen skills in the palliative approach.

Challenges that are consistent with other generalist members of the health workforce who may come in contact with women with a gynaecological cancer include:
- the variable and often limited contact that Aboriginal health and community workers may have with all cancer patients and/or women with gynaecological cancer
- the breadth of health areas that Aboriginal health and community workers have to cover.

Strategies to address these issues may include:
- identification of specific health workers with an interest in developing a level of ‘cancer knowledge’ to be a key contact and support for other workers and link visiting educators with the community
- development of networks of ‘cancer-specific’ Aboriginal health and community workers
- the provision of specific educational programs for female workers about gynaecological cancers (prevention, screening and treatment) for Aboriginal health and community workers framed within the context of ‘women’s business’
- the creation of strong partnerships between local general cancer and gynaecological cancer services with internal and community-based Aboriginal health and community services to ensure optimal care for Aboriginal and Torres Strait Islander people with cancer including women with gynaecological cancer. This includes:
  - strengthening the skills of Aboriginal health and community workers (such as Aboriginal hospital liaison officers) and supporting them in their work
  - strengthening the cultural competence of mainstream providers to work with Aboriginal and Torres Strait Islander people affected by cancer.

Table 11 identifies the specific skills that Aboriginal health and community workers need depending on whether they work regularly or occasionally with people with cancer and/or within the general community. (See page 60).
Table 11: Specific skills for Aboriginal health and community workers working in different service contexts

<table>
<thead>
<tr>
<th>Aboriginal hospital liaison officers and other Aboriginal health and community workers who work regularly with people with cancer and their families</th>
<th>Aboriginal health and community workers who work occasionally with people with cancer and their families</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Meet the general requirements of their role</td>
<td>• Meet the relevant requirements of their professional discipline</td>
</tr>
<tr>
<td>• Have a good general understanding of cancer, its treatment, outcomes and potential impact on Aboriginal and Torres Strait Islander people</td>
<td>• Understanding of the impact of cancer on individuals and families and those factors that might increase psychosocial distress</td>
</tr>
<tr>
<td>• Able to work with other members of the multidisciplinary cancer team to:</td>
<td>• Access to information on gynaecological cancers and their treatment to understand any specific impact on individual women and their families</td>
</tr>
<tr>
<td>– support Aboriginal and Torres Strait Islander patients with cancer and their families</td>
<td>• Ability and confidence to use and adapt their broad professional skills to assess and respond to the specific needs of individual women with cancer and their families</td>
</tr>
<tr>
<td>– provide guidance on the specific cultural needs of individual clients</td>
<td>• Skills in working with people experiencing loss and grief</td>
</tr>
<tr>
<td>– advocate on behalf of the individual or family</td>
<td>• Access to secondary consultation through linkages with colleagues who work regularly with women with gynaecological cancer and/or general cancer populations.</td>
</tr>
<tr>
<td>Able to work with individuals, families and communities who are emotionally distressed and/or experiencing loss and grief</td>
<td></td>
</tr>
<tr>
<td>Be familiar with and liaise with other mainstream cancer support and palliative care services to optimise patient access to relevant resources and programs</td>
<td></td>
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<tr>
<td>Have access to appropriate support and debriefing through the Aboriginal health service and/or the cancer team</td>
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Depending on the service context additional skills may include the ability to develop:

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<tr>
<td>specific knowledge to support women with a gynaecological cancer and their families</td>
<td>the other six services had varying levels of data management support ranging from 0.1 to 2 EFT (the service volume varied from 98–220 new cases per annum). It is unclear whether these resources are supported through core funding or through other funding mechanisms such as industry-driven clinical trials or philanthropic funding.</td>
</tr>
<tr>
<td>peer support programs for Aboriginal and Torres Strait Islander people with cancer</td>
<td>Cancer Australia has developed a national dataset specification for gynaecological cancers. This provides a starting point for more comprehensive data collection and analysis for the future. It is also essential that stage-related survival data becomes available nationally so that any variances in local or national outcomes can be identified and addressed.</td>
</tr>
<tr>
<td>Increased knowledge of the palliative approach to support people and families.</td>
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</table>

**2.14 Data management and clinical trial support**

While not providing a direct clinical role, access to adequate data management resources is essential to ensure that specialist gynaecological cancer services can optimise the use of clinical, epidemiological and service data for routine quality assurance activities as well as for supporting clinical trials and research. Data management support may be provided through different disciplines including health information managers and research nurses.

All 12 specialist gynaecological cancer services that completed the service mapping exercise developed to inform this National Framework indicated their participation in clinical trials (see Appendix H). However, this data also indicated that:

- six of the 12 services had no data management support with five of these services being high-volume services (i.e. 185–250 newly diagnosed women each per annum)
- the other six services had varying levels of data management support ranging from 0.1 to 2 EFT (the service volume varied from 98–220 new cases per annum).

Given that ‘continuous quality improvement, consumer feedback, clinical trials and research’ is one of the core elements of a quality gynaecological cancer service (see Service Element 8, Appendix F), there is strong support for resourcing adequate data management infrastructure to enhance the collection, entering and analysis of relevant data that:

- links in with the relevant minimal datasets
- optimises data collection across inpatient and outpatient settings and across sectors.

Cancer Australia currently provides some infrastructure support to the Australian and New Zealand Gynaecological Oncology Group (ANZGOG) and has funded a number of research initiatives over the past four years. However, there remains a need to access additional resources to support improving women’s participation in current and future clinical trials and the further development of cooperative and group investigator-initiated clinical trials.

Opportunities to access additional funding for clinical trials may come through Cancer Australia’s Priority-driven Collaborative Cancer Research Scheme or through more local organisations that fund research and clinical trials. It also requires continuing advocacy for stronger support for research and clinical trials infrastructure. In the absence of additional national or state/territory capacity in this area, the majority of gynaecological cancer research may continue to be industry-driven.
Appendixes
Appendix A

**Glossary**

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>Acute services</td>
<td>Describes a hospital where patients receive treatment for an episode of illness.</td>
</tr>
<tr>
<td>Advanced disease</td>
<td>This term typically refers to cancer that has spread beyond the organ or tissues where it originated and is unlikely to be curable.</td>
</tr>
<tr>
<td>Allied health providers</td>
<td>This group includes healthcare professionals – other than doctors and nurses – such as occupational therapists, dietitians, physiotherapists, social workers and others directly involved in the provision of health care.</td>
</tr>
<tr>
<td>Ambulatory care</td>
<td>Health care which is provided to patients either at a hospital or in the community, but treatment as an inpatient is not required.</td>
</tr>
<tr>
<td>Anatomic pathologist</td>
<td>A branch of pathology that examines changes in the structure and composition of organs and tissues as a result of disease.</td>
</tr>
<tr>
<td>Brachytherapy</td>
<td>A form of radiotherapy where radioactive seeds or sources are placed inside or next to the area requiring treatment. Can be used alone or in combination with surgery, chemotherapy or other treatments.</td>
</tr>
<tr>
<td>Cervical cancer screening</td>
<td>The organised program of regular testing of women using Pap smears to identify treatable pre-cancerous lesions on the cervix in asymptomatic women which, if left untreated, may develop into cancer of the cervix.</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>The use of chemical agents (drugs) to kill cancer cells.</td>
</tr>
<tr>
<td>Colposcopy</td>
<td>A medical diagnostic procedure using a colposcope – an illuminated binocular microscope that magnifies the view of the cervix, vagina and vulva – to identify abnormal tissue.</td>
</tr>
<tr>
<td>Co-morbidities</td>
<td>Co-existing medical conditions.</td>
</tr>
<tr>
<td>Culturally and linguistically diverse (CALD)</td>
<td>People from a CALD background have a specific cultural or linguistic affiliation due to their country of birth, ethnic origin, language(s) and/or family traditions.</td>
</tr>
<tr>
<td>Dietitian</td>
<td>Dietitians – or dieticians – specialise in the study of nutrition and its contribution to maintaining or restoring health.</td>
</tr>
<tr>
<td>Dosimetry</td>
<td>Accurate measurement of the dosage of radiation.</td>
</tr>
<tr>
<td>Epidemiologist</td>
<td>A person trained in investigating and describing the causes and spread of disease, and developing the means for prevention or control.</td>
</tr>
<tr>
<td>Fertility specialist</td>
<td>A doctor specialising in the investigation and treatment of people who have difficulty conceiving.</td>
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<tr>
<th>Term</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Geneticist and genetic counsellor</td>
<td>Geneticists study genes, heredity and genetic causes of human variations. Genetic counsellors offer information and testing to help determine the diagnosis, risk, carrier and pre-symptomatic status of genetic conditions.</td>
</tr>
<tr>
<td>Gynaecological cancer</td>
<td>This term refers to cancers that originate in a woman’s reproductive system, including cancers of the ovary, fallopian tube, uterus, cervix, vagina, vulva and placenta.</td>
</tr>
<tr>
<td>Gynaecological oncologist</td>
<td>Gynaecological oncologists are gynaecologists who have undertaken additional specialist training in the diagnosis and management of women with gynaecological cancers.</td>
</tr>
<tr>
<td>Gynaecologist</td>
<td>Gynaecologists are specialist doctors in the field of women’s reproductive systems. Gynaecologists investigate, diagnose and treat diseases of the reproductive system.</td>
</tr>
<tr>
<td>‘Hub and spoke’ model</td>
<td>A model of care in which one centre acts as a principal base for a particular service or range of services, providing support to a number of connected satellite centres.</td>
</tr>
<tr>
<td>Human papilloma virus (HPV) vaccine</td>
<td>This vaccine prevents infection with some types of HPV, including types 16 and 18 which are responsible for the majority (70% internationally, 80% in Australia) of cervical cancers and a significant proportion of some other genital cancers.</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>An operation to remove a woman’s uterus (womb).</td>
</tr>
<tr>
<td>Laparoscopic (keyhole) surgical technique</td>
<td>A modern, minimally invasive surgical technique in which operations in the abdomen are performed through small incisions.</td>
</tr>
<tr>
<td>Level IV evidence</td>
<td>In line with standards established by the National Health and Medical Research Council of Australia, Level IV evidence includes observational studies, including case reports, summaries of case reports and case series.</td>
</tr>
<tr>
<td>Lymphoedema practitioner</td>
<td>Health professionals involved in the treatment of lymphoedema, a condition in which patients experience fluid retention and tissue swelling, often of a limb, caused by a compromised lymphatic system.</td>
</tr>
<tr>
<td>Medical oncologist</td>
<td>Specialist doctors with training in the management of cancer using chemotherapy as the main treatment modality.</td>
</tr>
<tr>
<td>Menopause</td>
<td>The time in a woman’s life when the menstrual cycle ends.</td>
</tr>
<tr>
<td>Multidisciplinary care</td>
<td>An integrated team approach to health care in which medical, nursing and allied healthcare professionals consider all relevant treatment options and collaboratively develop an individual treatment plan for each patient.</td>
</tr>
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### Appendix A

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>Nurse – gynaecological cancer (or nurse coordinator/consultant)</td>
<td>A specialist cancer nurse who has specific expertise in supporting women with gynaecological cancers.</td>
</tr>
<tr>
<td>Nurse – palliative care</td>
<td>These nurses have specialist training in multidimensional symptom assessment and management, advanced care planning and coordination of palliative care services. They may provide inpatient, consultancy or specialist community-based support to patients.</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>These nurses have undertaken further (master’s level) training, and are authorised to function autonomously and collaboratively in an advanced and extended clinical role.</td>
</tr>
<tr>
<td>Palliative care (or specialist palliative care)</td>
<td>Specialised health care focusing on relieving and preventing the suffering of patients with life-threatening illness, including those with curable illnesses, chronic disease and those nearing the end of life.</td>
</tr>
<tr>
<td>Pastoral care</td>
<td>Spiritual support and guidance provided by chaplains and other care workers who have a broad understanding of the spiritual beliefs of people from diverse cultures.</td>
</tr>
<tr>
<td>Pathologist</td>
<td>Pathologists examine changes in the structure and composition of organs and tissues that occur as a result of disease.</td>
</tr>
<tr>
<td>Primary services</td>
<td>The patient’s first point of contact with the healthcare system before referral to specialist services. Primary services providers include GPs, nurses and pharmacists.</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>A physician with specialist training in mental illness. Psychiatrists can apply a range of modalities to diagnose, manage, treat and prevent mental and emotional illnesses.</td>
</tr>
<tr>
<td>Psychologist</td>
<td>Psychologists have specific training in the biological, cognitive and social causes of human behaviour, and apply this knowledge to help people overcome emotional and behavioural problems.</td>
</tr>
<tr>
<td>Psycho-oncologist</td>
<td>A specialist psychologist who focuses on patients’ and their families’ psychological responses to cancer, as well as emotional, behavioural and social factors that might impact on their cancer experience.</td>
</tr>
<tr>
<td>Psychosexual counsellor</td>
<td>A counsellor providing therapy to address a patient’s sexual concerns.</td>
</tr>
<tr>
<td>Psychosexual sequelae</td>
<td>Effects on emotional health and sexuality that arise from a particular experience, e.g. having a gynaecological cancer.</td>
</tr>
<tr>
<td>Psychosocial care</td>
<td>Care that relates to one’s practical, social and psychological needs with the aim of helping to control symptoms or distress and increase satisfaction with life. It can include practical advice, motivational, social and vocational training, structured counselling, support and guidance. The term psychosocial care may be used interchangeably with supportive care, although does not include physical aspects of care.</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>A medical doctor who specialises in treating cancer patients using radiation therapy as the main treatment modality.</td>
</tr>
<tr>
<td>Salvage surgery</td>
<td>Salvage surgery can be defined as surgery intended to eradicate all remaining or recurrent tumours. This may be provided to patients whose medical condition is unresponsive or unsuitable to treatment, given to reduce the severity of symptoms or to increase the quality of life.</td>
</tr>
<tr>
<td>Screen-detected abnormality</td>
<td>Abnormal results of a screening test, e.g. a Pap smear, that indicate further assessment is required to confirm or exclude the presence of cancer.</td>
</tr>
<tr>
<td>Secondary consultation approaches</td>
<td>Clinical advice and support provided by one health professional to another health professional about a specific patient. The advisor may or may not have any direct contact with the patient.</td>
</tr>
<tr>
<td>Service mapping</td>
<td>The process of identifying the range of services available to the community to support particular patient groups, e.g. cancer patients. These services might include diagnostic services, specialist services and primary care services. Service mapping also involves working out how and when services can be accessed and linked to provide continuity of care.</td>
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Appendix A

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<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>Shared care</td>
<td>Cooperation between different groups of clinicians to provide agreed aspects of care given to patients.</td>
</tr>
<tr>
<td>Squamous cell and glandular cell abnormalities</td>
<td>Squamous cells are found on the surface of the skin and in several organs of the body. Glandular cells are cells which secrete a substance such as hormones, mucus or lubricating fluid. Cancers of squamous cells are called squamous cell carcinomas and cancers of glandular cells are called adenocarcinomas. An abnormal appearance of either of these cell types may indicate further testing is required to confirm or exclude cancer.</td>
</tr>
<tr>
<td>Sub-specialty</td>
<td>Additional specialist training in a particular sector of one of the main medical specialties. For example, gynaecological oncologists are sub-specialists of the specialty of obstetrics and gynaecology.</td>
</tr>
<tr>
<td>Supportive care providers</td>
<td>These include social workers, psychologists, psychiatrists, sexual counsellors, pastoral care providers and other allied health providers who address a range of social, practical, psychological, spiritual and physical needs.</td>
</tr>
<tr>
<td>Treatment plan</td>
<td>A written document outlining the commencement, approach, goals and progression of therapy.</td>
</tr>
<tr>
<td>Woman-centred care</td>
<td>This model embraces the woman’s right to self-determination in her choice of care. It embraces the patient’s social, emotional, physical, cultural and other needs.</td>
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Appendix B

Project method for developing the National Framework

The following outlines the project objective and scope, key strategies and the guiding principles that informed the development of the National Gynaecological Cancers Service Delivery and Resource Framework.

Project objective and scope

The specific project objective was to develop a national service delivery and resource framework that will guide future service development and improvements in the care of all women with gynaecological cancers.

Key elements of the project were to:

- Identify the needs of women, their families and carers across the gynaecological cancers illness trajectory, including women in rural and remote areas, Indigenous women and women from culturally and linguistically diverse backgrounds
- Identify and estimate the number and range of clinicians and trainees (and support staff) required to meet the current and projected incidence of gynaecological cancers across Australia across the patient journey including palliation
- Define the multidisciplinary teams and their composition and determine the minimum and maximum caseload for such teams
- Describe best-practice agreed referral pathways spanning private and public sectors
- Identify the professional development requirements of the primary and specialist gynaecological cancers workforce
- Develop an approach to improved identification of Aboriginal and Torres Strait Islander women with gynaecological cancers
- Identify support structures that facilitate best practice for small gynaecological oncology multidisciplinary teams
- Identify research requirements and appropriate access to clinical trials.

The primary focus of the project was on the management of women with gynaecological cancers. However, given the nature of some gynaecological cancers including pre-cancerous conditions and family history, the project scope included all parts of the pathway journey from prevention to palliation.

Within this context, the National Framework addresses the early pathway point of ‘reducing risk and finding gynaecological cancer early’.

Project advisory mechanisms

The development of the National Framework was guided and supported by a Project Working Group and a Consumer Reference Group (see Appendix C for memberships).

Guiding principles

The following principles guided the development of the National Framework:

A strong consumer focus to ensure that the framework is guided by the needs of women with gynaecological cancer and their families and carers

A collaborative approach working with key stakeholders to ensure that the National Framework is informed by a diversity of views and perspectives

Building on current work to avoid duplication of effort

Realistic perspectives on the challenges facing the current and future workforce with a key focus on ‘ensuring the best use of available resources’.

Project strategies

The following strategies were undertaken to inform the National Framework:

Epidemiological and other service/service provider data: Data was accessed through published AIHW reports and unpublished data made available through individual services, jurisdictions or through the AIHW or RANZCOG.

The literature review: The literature review focused on the key evidence about the needs of women, evidence-based practice guidelines, patterns of care for service delivery and reviewing reports from other work commissioned by the NGCC.

Service mapping exercise: Each of the related jurisdictional projects coordinated the completion of a service mapping tool from 12 gynaecological cancer services across Australia. This mapping exercise was aimed at identifying local service demand; multidisciplinary team members, resources and practices, referral pathways and linkages and strategies to address the needs of specific groups of women (see Appendix H for a summary of key findings).
Appendix C

Project advisory mechanisms

This appendix lists the members of the Consumer Reference Group and Project Working Group, and staff of Cancer Australia, who provided advice and support in the development of the National Framework.

Consumer Reference Group

Ms Lorraine Cooper  Consumer, Victoria
Ms Maureen Hannan  Consumer, NSW
Ms Alison Harris  Carer, NSW
Ms Lesley McGuire  Member of the NCCG Advisory Group
Ms Jane Mills  Consumer, NSW
Ms Connie Nikolski  Member of the Project Working Group
Ms Stephanie Perrott  Consumer, South Australia
Ms June Sparks  Consumer, Western Australia
Ms Tania Sword  Consumer, NSW
Ms Merran Williams  Consumer, Queensland

Project Working Group

Dr Gerry Walsh (Chair)  Director, Gynaecological Oncology Services, Westmead Hospital, Sydney
Ms Alise Bean-Hodges  Nurse practitioner, Royal Women’s Hospital, Melbourne. Representative of Royal College of Nursing, Australia
Dr James Brodribb  Gynaecologist, Tasmania, RANZCG representative
Dr Gabrielle Casper  Gynaecologist, NSW, Australasian Gynaecological Endoscopy and Surgery Society
Dr Katherine Clarke  Palliative care physician, NSW Member of NCCG Advisory Group
A/Prof Margaret Davy  Gynaecological oncologist, Royal Adelaide Hospital. Member of NCCG Advisory Group
Ms Cecily Dollman  Social worker, Royal Adelaide Hospital
Ms Susan Hanson  National Manager, National Centre for Gynaecological Cancers and Consumer Networks, Cancer Australia
Dr Pearly Khaw  Radiation oncologist, Peter MacCallum Cancer Centre, Melbourne Representative of the Royal Australian and New Zealand College of Radiologists
Ms Letitia Lancaster  Specialist nurse, Gynaecological Oncology Services, Westmead Hospital, Sydney Member of NCCG Advisory Group
Dr Yee Leung  Gynaecological oncologist, King Edward Memorial Hospital for Women, Perth
Dr Linda Milethkin  Medical oncologist, Peter MacCallum Cancer Centre, Melbourne Representative of the Medical Oncology Group of Australia
Ms Jane Mills  Consumer, NSW Member of the Consumer Reference Group
Ms Connie Nikolski  Consumer, Victoria Member of the Consumer Reference Group
Ms Ann Robertson  Manager, Women’s Health Services, RANZCOG
Dr Katharine Salmond  General practitioner, Tasmania
Ms Pauline Tannor  Specialist nurse, Gynaecological Oncology Services, WA
Ms Robyn Thomas  Acting Manager, Quality and Clinical Collaborations, Cancer Institute NSW Project officer for the NCCG Jurisdictional Project in NSW
Dr Jo Wainer  Australian Council for Regional and Rural Medicine
Ms Kathryn Whittfield  Manager, Cancer Reform, Department of Health, Victoria

Cancer Australia

Ms Ella Curnow  Acting Assistant Director, National Centre for Gynaecological Cancers
Ms Susan Hanson  National Manager, National Centre for Gynaecological Cancers and Consumer Networks
Ms Julie Mueller  Assistant Director, National Centre for Gynaecological Cancers
Dr Joanne Ramadge  Deputy Chief Executive Officer
Appendix D

Consultation and workshop participants
This appendix lists those participants who:
- participated in the initial consultation
- provided individual advice through the development or revision of the National Framework
- participated in the national workshop held in April 2010.

Consultation participants and individual advisors

<table>
<thead>
<tr>
<th>Name</th>
<th>Discipline/role</th>
<th>Jurisdiction</th>
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<tr>
<td>Dr James Brodie</td>
<td>Gynaecologist</td>
<td>Tasmania</td>
</tr>
<tr>
<td>Dr Will Cairns OAM</td>
<td>Palliative care physician</td>
<td>Queensland</td>
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<tr>
<td>Ms Nicole Cameron</td>
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<tr>
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<td>Dr Gabrielle Casper</td>
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<td>Ms Sharon Clarke</td>
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<tr>
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<td>Director, Cancer Redevelopment, WA Health</td>
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<td>Dr Paul Davey</td>
<td>Director of Obstetrics and Gynaecology, Ballard Base Hospital</td>
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<td>A/Prof Margaret Davy</td>
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<td>Dr Anna De Fazio</td>
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<td>Ms Jane Francis</td>
<td>Manager, Ovarian Cancer Program, NBOCC</td>
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<td>Ms Sprit Galletakis</td>
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<td>Ms Helen Gray</td>
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<td>Dr Kerryn Ireland-Jenkins</td>
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<td>Ms Catherine Jacka</td>
<td>Researcher, Aboriginal health issues</td>
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<td>Ms Meagan Judge</td>
<td>Program manager, RCWA</td>
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<td>Dr Ilona Juraskova</td>
<td>Behavioural scientist</td>
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<td>Prof Dorothy Keefe</td>
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<td>Dr Pearly Khair</td>
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<tr>
<td>Dr Olga McNally</td>
<td>Gynaecological oncologist</td>
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## Appendix D

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<td>Ms Carmel McNamara</td>
<td>Coordinator, Aboriginal Cancer Control Program</td>
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<td>Ms Lesley McGuire</td>
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<td>Ms Nicole Cameron</td>
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<td></td>
<td>Department of Health, member, Cancer Australia’s</td>
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<td>Dr Gabrielle Casper</td>
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## Appendix D

### National workshop participants

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<tr>
<td>Dr Robyn Cheuk</td>
<td>Radiation oncologist, NGCG Advisory Group</td>
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<tr>
<td>Ms Geraldine Cleary</td>
<td>National evaluation consultant, Siggins Miller</td>
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<tr>
<td>Ms Kathryn Crisell</td>
<td>Consumer, NGCG Advisory Group</td>
<td>South Australia</td>
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<tr>
<td>Ms Ella Cunow</td>
<td>NCRC, Cancer Australia</td>
<td>National</td>
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<tr>
<td>AvProf Margaret Davy</td>
<td>Gynaecological oncologist, NGCG Advisory Group; Project Working Group</td>
<td>South Australia</td>
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<tr>
<td>Ms Cecily Dellman</td>
<td>Social worker, Project Working Group</td>
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<td>Ms Judith Eddy</td>
<td>Specialist gynaecological cancer nurse</td>
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<td>Ms Jane Francis</td>
<td>Manager, Ovarian Cancer Program, NBCC</td>
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<td>Ms Helena Green</td>
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<td>AvProf Neville Hacker</td>
<td>Gynaecological oncologist</td>
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<td>Ms Susan Hanson</td>
<td>National Manager, National Centre for Gynaecological Cancers and Consumer Networks, Cancer Australia</td>
<td>National</td>
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<td>Ms Jane Harris</td>
<td>Consumer, NGCG Advisory Group</td>
<td>ACT</td>
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<tr>
<td>Ms Kim Hobbs</td>
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<td>Ms Alison Hocking</td>
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<tr>
<td>Dr Cameron Hurter</td>
<td>Physician; member, Cancer Australia’s Strategic Forum</td>
<td>Tasmania</td>
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<tr>
<td>Prof Dorothy Keefe</td>
<td>Professor of Medicine (medical oncology); Member, Cancer Australia’s Strategic Forum</td>
<td>South Australia</td>
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<td>Dr Pearth Khaw</td>
<td>Radiation oncologist, Project Working Group</td>
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<td>AvProf Rosemary Knight</td>
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</tr>
<tr>
<td>Ms Letitia Lancaster</td>
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<tr>
<td>Dr Danette Langberger</td>
<td>Project Officer for NGCG Jurisdictional Project in Queensland</td>
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<td>Ms Lesley McGuire</td>
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<td>General practitioner, Victorian Aboriginal Community Controlled Health Organisation</td>
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<td>Acting CEO, Cancer Australia</td>
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<td>Ms Georgia Richter</td>
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<tr>
<td>Dr Katharine Salmon</td>
<td>General practitioner; NGCG Advisory Group</td>
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## Appendix D

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<tr>
<td>Dr Meg Sands</td>
<td>Palliative care physician</td>
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<td>Ms Irene Schluter</td>
<td>Project Officer for NCIC Jurisdictional in South Australia</td>
<td>South Australia</td>
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<td>Ms Sue Sinclair</td>
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<td>Ms Robyn Thomas</td>
<td>Acting Manager; Quality and Clinical Collaborations,</td>
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<tr>
<td>Ms Cherie Wright</td>
<td>Project Officer, Victorian Aboriginal Community Controlled Health Organisation; NCIC Advisory Group</td>
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<tr>
<td>Dr Gerry Wain</td>
<td>Gynaecological oncologist; Chair, Project Working Group</td>
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<td>Ms Mieran Williams</td>
<td>Consumer, Consumer Reference Group</td>
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<td>Mr Peter Williams</td>
<td>Manager, Multidisciplinary Care, Department of Health</td>
<td>Victoria</td>
</tr>
<tr>
<td>Dr Regina Wulf</td>
<td>Gynaecologist</td>
<td>Northern Territory</td>
</tr>
</tbody>
</table>

## Appendix E

### Detailed summary of women’s needs

<table>
<thead>
<tr>
<th>Area of need</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Timely access to services** | - Avoiding unnecessary delay in diagnosis and referral through:  
  - increasing women’s and general providers’ awareness of cancer symptoms  
  - good referral pathways that minimise delay including access to secondary consultation for the referring practitioner;  
  - Optimising timely access to treatment by reducing waiting times for specific clinicians’ availability, access to inpatient beds and theatre time.  
  - Access to allied health and supportive care providers across the pathway.  
  - Access to local services where possible for regional and remote women.  
  - Timely access back into the system if women have symptoms of recurrence or other side-effects that require assessment, management or referral.  
  - Timely access to services able to deal with complex symptom management associated with advanced disease and end-of-life care. |
| **Optimal clinical and multidisciplinary management according to best practice** | - All women with a confirmed or suspected cancer have access to best practice care in accordance with evidence-based guidelines.  
  - All women have access to multidisciplinary treatment planning or case discussion which must include involvement of a gynaecological oncologist prior to treatment for proven or suspected cancer.  
  - Women have access to all relevant clinical trials.  
  - Optimal management of co-morbidities, acute complications and side-effects.  
  - Assessment and management of long-term side-effects or late effects.  
  - Access to optimal symptom relief for women with advanced cancer and strategies to facilitate transition or appropriate referral to palliative care. |
| **Access to a ‘safe’ physical, emotional and cultural environment** | - Women nursed in women-only wards and ideally with women with similar conditions and not within a maternity unit.  
  - Cultural sensitivity and flexibility to meet the diverse needs of all women and in particular the specific needs of Aboriginal and Torres Strait Islander women and women from CALD backgrounds.  
  - Access to female providers to respond to individual women’s preferences.  
  - Attention paid to the communication skills of all healthcare professionals to ensure sensitive responses to women, building women’s confidence in their providers and providing a sense of hope.  
  - Attention paid to appropriate ambulatory care (clinic) environments and organisation to reduce waiting times and enhance unavoidable waiting times. |
### Area of need

<table>
<thead>
<tr>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensuring smooth transitions across services for women and their families.</td>
</tr>
<tr>
<td>Clear pathways and inter-team communication to optimise care.</td>
</tr>
<tr>
<td>The need for an identified key contact for women at all disease stages and ensuring that women have the knowledge, skills and support to navigate the system.</td>
</tr>
<tr>
<td>The multidisciplinary team works closely with internal and external Aboriginal health workers and ‘cultural brokers’ within their community to facilitate Aboriginal and Torres Strait Islander women’s optimal access to treatment and support.</td>
</tr>
<tr>
<td>Timely communication with general practitioners and community services to ensure women’s optimal access to local care post-discharge as needed.</td>
</tr>
<tr>
<td>Timely communication and coordination between multiple providers to facilitate streamlined follow-up care.</td>
</tr>
<tr>
<td>Women have access to a clear follow-up and survivorship plan.</td>
</tr>
</tbody>
</table>

### Psychosocial care needs including psychological and spiritual needs

<table>
<thead>
<tr>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to acknowledge and address the emotional impact of cancer on women and their families and take into consideration their roles within their families and communities and the impact of other life experiences such as sexual assault and mental health illnesses on their cancer experience.</td>
</tr>
<tr>
<td>Routine screening/assessment of psychosocial needs at key pathway points including ongoing survivorship; particular attention must be paid to those with identified risk factors for long-term psychosocial distress.</td>
</tr>
<tr>
<td>Access to a range of psychosocial and spiritual care providers in response to identified needs including low-cost counselling.</td>
</tr>
<tr>
<td>Emotional support provided within a wellness and empowerment model.</td>
</tr>
<tr>
<td>Access to peer support programs for all women.</td>
</tr>
<tr>
<td>Ensure Aboriginal and Torres Strait Islander women and women from CALD backgrounds gain access to appropriate and culturally sensitive community and peer support.</td>
</tr>
</tbody>
</table>

### Practical needs

<table>
<thead>
<tr>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to financial support and practical advice.</td>
</tr>
<tr>
<td>Regional and remote women and carers gain access to relevant travel and accommodation support to reduce the burden of treatment.</td>
</tr>
<tr>
<td>Strategies put in place to assist Aboriginal and Torres Strait Islander women, especially from remote areas, and their support person when facing a long period of treatment within an alien environment.</td>
</tr>
</tbody>
</table>

### Addressing psychosexual needs and fertility issues

<table>
<thead>
<tr>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early assessment of women’s fertility or sexual concerns and needs and identification of women who are at high risk of experiencing fertility or psychosexual difficulties.</td>
</tr>
<tr>
<td>Information, support and strategies proactively provided to address fertility and sexuality concerns at diagnosis, treatment and recovery to optimise adjustment.</td>
</tr>
<tr>
<td>Service providers proactively initiate discussion with women about ongoing or new fertility or psychosexual needs and facilitate referral as needed.</td>
</tr>
</tbody>
</table>
Appendix F

The eight service delivery elements in detail
This appendix details the four pathway elements and four supporting elements that make up the National Framework. Each pathway point or supporting element has:
- an objective
- a rationale based on evidence from the literature and from women’s and service providers’ perspectives
- a number of service delivery components that address the objective and a series of supporting systems and processes that may be required to achieve them.

1. Reducing risk and finding gynaecological cancer early

Objective
Women have timely access to services and programs to optimise prevention, risk reduction and early diagnosis for gynaecological cancers and related cancers.

Rationale
This pathway point addresses the need to prevent cancer, reduce the risk of gynaecological cancer or detect cancer early and is predominantly undertaken through primary healthcare services.

General population
General health promotion strategies include the need to encourage healthy eating and exercise to reduce obesity, address smoking practices and other health practices to enhance women’s general health and wellbeing as well as reducing their cancer risk. Until relatively recently cervical screening with the Pap test has been the only major strategy for preventing the development of cervical cancer. Since the introduction of an organised approach to cervical screening, the incidence of cervical cancer has fallen. While screening will not detect all cervical cancers, women who still develop cervical cancer are more likely to have a poor screening history.

Women who may have lower screening rates include:
- women from regional and remote areas
- Aboriginal and Torres Strait Islander women
- women from culturally and linguistically diverse backgrounds
- women with disability.

The introduction of the HPV vaccine for young women will reduce the cervical cancer incidence over the next 20 years. National guidelines are also available to guide the management of asymptomatic women with screen-detected abnormalities. Women with a familial cancer history
About 10% of women with ovarian and early onset endometrial cancer are due to germ line mutations in hereditary cancer predisposing genes. These women and others with a family history of cancer (particularly ovarian and breast) require additional information, advice and referral to family cancer clinics for further consultation, genetic testing and if necessary appropriate strategies to reduce risks.

Women with symptoms suggestive of gynaecological cancer
There is evidence from the literature and from consumer and stakeholder consultations about significant delays in diagnosis and timely referral to gynaecological oncologists, and that a proportion of women with a high risk of malignancy are only referred to a gynaecological oncologist after initial surgery. There is currently specific guidance available that:
- supports GPs to assess women with unexplained persistent symptoms suggestive of ovarian cancer
- clearly identifies the need for rapid assessment processes for women with symptoms that may be suggestive of gynaecological cancer
- indicates that women with a confirmed cervical cancer or with cervical abnormalities suggestive of invasive cancer should be referred to a gynaecological oncologist, ideally within two weeks.

Service delivery components
The following outlines key service delivery components for reducing risk and finding gynaecological cancer early and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely access to prevention and risk reduction services for all women including:</td>
<td>- Community education for all women about health promotion, disease prevention and screening.</td>
</tr>
<tr>
<td>health promotion strategies including nutrition, exercise and smoking practices</td>
<td>- Primary and community health providers have the knowledge and skills to provide prevention and screening services to ‘at risk’ women.</td>
</tr>
<tr>
<td>HPV vaccination for young women</td>
<td>- Women with an abnormal Pap test are evaluated and managed according to the relevant NHMRC guidelines including referral pathways to colposcopy services.</td>
</tr>
<tr>
<td>routine cervical cancer screening</td>
<td>- Strategies are in place to address the health promotion and screening needs of disadvantaged and poorly screened women including those from regional and remote areas. Aboriginal and Torres Strait Islander women, women from culturally and linguistically diverse backgrounds and women with low literacy or disability. This includes access to a female provider.</td>
</tr>
<tr>
<td>management of women with a screen-detected abnormality</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to gynaecological cancer risk reduction, surveillance for women at high risk of gynaecological and other cancers</td>
<td>- Service providers including primary care providers have knowledge and skills to refer women to appropriate services including family cancer clinics in accordance with key guidance.</td>
</tr>
<tr>
<td></td>
<td>- Clear referral pathways to familial cancer services for women at high risk.</td>
</tr>
<tr>
<td></td>
<td>- Familial cancer services have appropriate criteria for referral in testing and counselling and referral to management services.</td>
</tr>
<tr>
<td></td>
<td>- Women are provided with appropriate information to guide their decision-making.</td>
</tr>
</tbody>
</table>

| Timely and appropriate response to women presenting with symptoms suggestive of gynaecological cancer | - Education of women and general providers (including gynaecologists) to recognise and respond appropriately to early symptoms and appropriately assess the risk of malignancy. |
| | - Clear referral pathways and effective triaging processes in place. |
| | - Systems and processes in place to facilitate rapid assessment of women with symptoms suggestive of or with confirmed cancer. |
| | - Secondary consultation undertaken with a gynaecological oncologist by gynaecologists or general surgeons when cancer may be suspected prior to initial surgery. |
Appendix F

2. Multidisciplinary team, management and support during treatment

Objective
All women with a confirmed or ‘suspected’ cancer or with recurrent cancer have access to best practice care including multidisciplinary treatment planning which includes input from a gynaecological oncologist and is in accordance with the best available evidence.

Rationale
‘Ideally all women with gynaecological cancer would have access to a specialist service with a multidisciplinary approach.’

Multidisciplinary care is seen as the cornerstone of optimal cancer care and facilitates effective treatment planning, adherence to evidence-based guidelines and care coordination.\(^\text{101, 102}\)

Based on national and more local evidence-based guidelines\(^\text{103, 104}\) for the management of ovarian cancer and on feedback from stakeholders, the multidisciplinary team for managing all women with gynaecological cancer includes the following disciplines:
- gynaecological oncologist (lead role)
- gynaecologist
- medical oncologist with expertise in gynaecological oncology
- pathologist with expertise in gynaecological oncology
- radiation oncologist with expertise in gynaecological oncology
- radiologist with expertise in gynaecological cancer
- specialist palliative care providers
- geneticist and genetic counsellors
- other medical specialists such as fertility and menopause specialists
- general practitioner
- nurse(s) with specialist knowledge in gynaecological cancer
- allied health services including:
  - social workers
  - dietitians
  - physiotherapists
  - lymphoedema practitioners
  - pharmacists
  - psychologists and psychiatrists
  - psychosexual counsellors
- spiritual and pastoral care providers
- other service providers such as interpreters, Aboriginal health workers and other community providers.

This is an extensive but not exhaustive list. It reflects the range of providers who may be involved in women’s care depending on their disease, the pathway point and their particular needs. The membership of specific multidisciplinary team meetings (or other decision-making processes) varies depending on the meeting purpose and service context.

While multidisciplinary team planning meetings are seen to be gold standard, the evidence of their specific impact on women’s outcomes compared with other multidisciplinary processes is more limited. However, other benefits of multidisciplinary meetings include improved quality and coordination of care and team communication and support.

From the consultation, there was clear evidence of multidisciplinary care planning particularly within the specialist centres, with some centres including discussion from patients from other public, private or regional services. This was facilitated by videoconferencing across metropolitan and regional services by at least one service.

In addition there was evidence of multidisciplinary supportive care meetings to facilitate support for women (see also Service Delivery Element 8).

Service delivery components
The following outlines key service delivery components for multidisciplinary management and support during treatment and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
</table>
| The multidisciplinary team | - Multidisciplinary team clearly identified and documented including the membership of different multidisciplinary treatment and care planning processes.  
- Formal policies and protocols are in place to guide multidisciplinary team planning processes and documentation of outcomes. |
| Multidisciplinary assessment and planning prior to major surgery for women with suspected cancer | - Multidisciplinary planning processes routinely include consultation with a gynaecological oncologist prior to surgery (or other treatment) for suspected gynaecological cancer. |
| Multidisciplinary treatment planning prior to women’s definitive surgery / other treatment for confirmed gynaecological cancer | - Clear processes in place for multidisciplinary planning prior to definitive treatment.  
- Strategies in place to facilitate multidisciplinary treatment planning when specific team members are unavailable, e.g. the use of technology and/or clear protocols for agreed ‘low risk’ patients.  
- Discussions of any supportive care issues that will impact on treatment decisions are integrated into multidisciplinary treatment planning.  
- Women are aware of and consent to their case being discussed by the multidisciplinary team.  
- Results of audit of multidisciplinary planning are reviewed to assess current practice against evidence-based guidelines. |
| Management of women with recurrence and advanced disease | - Women with recurrence are discussed by the multidisciplinary team, including specialist palliative care providers as needed, to ensure optimal access to appropriate treatment modalities, clinical trials, complex symptom management and palliative care. |
| Communication of multidisciplinary planning outcomes | - Outcomes of multidisciplinary treatment planning are recorded in the medical record.  
- A written treatment plan is given to women and communicated to their general practitioner. |
| Optimal management of the cancer and acute complications and side-effects including pain management | - Mechanisms in place to routinely review practice against evidence-based guidelines.  
- All service providers have the appropriate skills and knowledge to manage gynaecological cancer, and acute complications and side-effects.  
- Approaches are adopted to ensure women understand and recognise symptoms that require consultation. |
| Clinical trials availability and uptake | - Mechanisms are in place to routinely review women’s eligibility to participate in clinical trials and to inform women of their choices (see Service Delivery Element 8). |
Appendix F

3. Follow-up and survivorship

Objective

After completion of treatment, all women receive appropriate and flexible follow-up care that is responsive to their needs and optimises the best use of valuable resources, and is based on the best available evidence.

Rationale

As the number of people who are successfully treated for cancer rises,106 cancer ‘survivorship’ is being increasingly recognised as a distinct phase in the cancer journey.107 There is also evidence of the need for more structured approaches to proactively address survivorship issues informed by a strong wellness and empowerment approach.107 The four aims of survivorship care outlined in the literature are:

- prevention and detection of new cancers and recurrent cancers
- surveillance for cancer spread, recurrence or second cancers
- interventions to deal with the consequences of cancer and its treatment
- coordination between specialist and primary care providers.

However, follow-up consultations for all cancer patients predominantly focus on detecting cancer recurrence. Different service models to facilitate improved follow-up and survivorship models include GP-based models of care and shared models of care between specialist providers and GPs or specialist nurses. Evidence from trials demonstrates no differences in the quality of care or recurrence detection in different service models.108

Recommended strategies to promote ideal survivorship care include:

- clinical guidelines for follow-up
- screening and management of supportive care issues
- education and training of the workforce
- survivorship care plans.

While more research is needed, other approaches highlighted include information sharing, communication between the individual, family members and the cancer team, patient and caregiver empowerment and self-identification of need, and peer support.109

Within gynaecological cancer services, current follow-up practices which may be based on local follow-up guidelines (e.g. Victorian guidelines)109 generally:

- highlight that follow-up care reduces over time but may continue for many years
- align with the four survivorship aims outlined above
- indicate that follow-up care occurs predominantly within specialist services with some shared care approaches in place for individual regional women.

Challenges identified in current follow-up and survivorship practices include the service burden of ongoing follow-up for increasing numbers of women, variance of follow-up practices and time constraints limiting the capacity to address the short- or long-term issues that women might face.

Consumers endorsed the important role of follow-up care that identified recurrence or new cancers, addressed short- and long-term side-effects and ensured linkage with other service providers. However, their experience of follow-up was variable; for example, from the consumer survey undertaken as part of this work:

- 100% of women indicated ‘early detection of recurrence’ was an important element of follow-up care and 88% rated this aspect of current care as being good or very good
- 70% rated ‘assessing and managing menopause’ was important and 50% rated this aspect of current care as being good or very good and 27% as poor or very poor.

Consumers were supportive of follow-up care being provided by other providers and identified the following elements that were required to optimise their confidence:

- a consultation at treatment completion and provision of a ‘survivorship plan’ that:
  - reviews information about treatment and progress
  - identifies potential short- and longer term issues and strategies to address these
  - identifies a clear plan for future follow-up by different providers
  - a period of shared care between specialist and other providers to facilitate transition
  - a focus on empowering women to play an active role in their follow-up care
  - generalist providers are given clear guidance on the follow-up care and a good two-way information flow exists between specialist services and generalist providers
  - easy referral back for specialist advice when needed.

Service delivery components

The following outlines key service delivery components for follow-up and survivorship and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women have a clear follow-up plan after treatment</td>
<td>- There is an agreed approach to the follow-up care of all women after treatment including providing a follow-up plan tailored to women’s assessed current clinical and supportive care needs.</td>
</tr>
<tr>
<td>Follow-up care is provided by the appropriate service provider based on the woman’s condition, time since treatment completion and needs</td>
<td>- Clear and consistent follow-up policies and protocols are implemented to ensure appropriate assessment and management and the optimal use of resources balanced with flexibility to respond to individual women’s needs.</td>
</tr>
<tr>
<td>Optimal assessment and management of short- and long-term side effects including fatigue, fertility, menopausal symptoms, emotional distress and practical concerns</td>
<td>- Different approaches to providing follow-up care are trialed and evaluated and if successful and sustainable are implemented into routine practice.</td>
</tr>
<tr>
<td>Women with possible recurrence or other side-effects or needs have timely access back into the system, as needed</td>
<td>- Providers of follow-up care have clear knowledge and skills:</td>
</tr>
</tbody>
</table>
  - to routinely assess and appropriately manage all identified short- and long-term side-effects
  - of the range of services available to support women.
  - There are clear referral pathways, triage processes and information flow for women who require more specialist management or advice within and across service sectors. |
| Optimal information flow between providers | - There are processes and protocols to guide rapid access to specialist services as required. |
  - A key contact is available for women or the follow-up service provider to facilitate advice and referral to specialist providers. |

[ BACK TO CONTENTS ]
Appendix F

4. Advanced disease and palliative care

Objective
Women have access to multidisciplinary planning and review, appropriate treatment, symptom management and palliative care services to optimise their quality of life.

Rationale
Just over one third (37%) of women with gynaecological cancer will die of their disease and may need access to generalist or specialist palliative care services. Information and support must also be available for their carers.

A major component of palliative care involves a patient-centred approach and optimal symptom relief which may require surgical intervention, radiation therapy or chemotherapy. In addition, the symptom burden for some women may be significant, interfering with their ability to live well. Early referral to specialist palliative care providers to facilitate optimal symptom management during further treatment is essential.111

A range of clinical practice guidelines are available to support optimal palliative care for all patients including communicating with adults with advanced disease and guidance specifically for women with gynaecological cancers.112,113

Depending on variations in how palliative care services are provided within different jurisdictions, palliative care using the palliative approach may be offered through generalist (non-specialist) providers within acute services or the community sector, e.g. inpatient medical and nursing staff, GPs or district nursing services, or through specialist palliative care services (including medical, nursing, allied health and bereavement specialists).114

Specialist palliative care services may be available through:
- specialist inpatient palliative care units (hospices)
- community-based specialist palliative care services providing support in the home
- inpatient specialist palliative care medical and/or nursing consultants who provide advice and support for patients within general inpatient facilities and coordinate patient transfer to specialist inpatient palliative care services or community-based services.

There was some evidence of palliative medicine, nursing and/or allied health specialists being well integrated into the gynaecological cancer service team and being actively involved in:
- inpatient multidisciplinary case discussion and treatment planning
- management of complex symptoms in women across all disease phases as well as those with incurable disease
- responding to early referrals for complex symptom management for those patients still in active treatment
- providing secondary consultation to generalist providers
- liaison and referral to other specialist palliative care providers and other services in the community.

Service gaps identified included:
- the need for earlier referral to specialist palliative care providers
- the need to strengthen skills of all members of the multidisciplinary team in managing physical symptoms including pain, gastrointestinal symptoms and emotional distress
- the need for appropriately detailed and timely medical, nursing and allied health information flow to specialist palliative care providers in any settings
- lack of access to specialist palliative care providers across many areas including tertiary centres, other metropolitan service settings and in regional and remote areas
- women from regional Australia are at times unnecessarily transferred back to their specialist centre for symptom management which could be managed within their local community enabling them to have good symptom management and end-of-life care at home or as close to home as appropriate.

Service delivery components
The following outlines key service delivery components for managing women with advanced cancer and requiring palliative care and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
</table>
| Early referral to specialist palliative care providers and general (non-specialist) palliative care providers | • Specialist palliative care providers (medicine, nursing and allied health) are active members of the multidisciplinary team and:
  - participate in multidisciplinary treatment planning and inpatient case discussion
  - ensure early detection, assessment and management of symptoms and end-of-life care needs and appropriate care planning
  - ensure appropriately detailed medical, nursing and allied health referral information within and across services and sectors
  - facilitate liaison, review and support with other providers in accordance with established referral pathways, protocols and processes.
  - Good communication is maintained with the woman’s general practitioner to facilitate local support and the transition to home-based palliative care and bereavement services.
  - Services have clear information about external specialist palliative care services and community services to facilitate referral and optimal management and support of women and their carers within their community. |

| Services have access to advice and support for optimising physical and psychosocial symptom management including pain, gastrointestinal symptoms and psychological distress | • All service providers involved in the management and care of women with advanced gynaecological cancer have the skills and knowledge to:
  - communicate well with women and their carers
  - manage common physical and psychosocial symptoms
  - refer early and appropriately to specialist palliative care providers and services
  - ensure appropriate care planning and symptom management. |

Addressing the needs of women from diverse backgrounds with advanced disease and their families

| Strategies are in place to acknowledge, respect and integrate the different cultural needs and traditions of all women from diverse backgrounds and their families as women approach their death. | • Strategies are in place to increase understanding by the centralised treating team of the importance of optimising early and ongoing linkage and communication with general and specialist regional service providers including regional specialist palliative care providers to ensure that regional women can receive optimal palliative care to end-of-life care as close to home as possible, and that unnecessary travel to metropolitan centres is avoided.
  - Every effort is made to ensure that Aboriginal and Torres Strait Islander women, their families and communities are supported to enable them to “return to country” as they choose and while they are still physically able to do so. |
Appendix F

5. Woman-centred environment

Objective
Women receive care that is sensitive to the diversity of their individual needs and is provided in an appropriate physical, emotional and cultural environment.

Rationale
I shared a room with a woman who had just had a baby and it was not ideal. I was in shock from my diagnosis and dealing with life and death issues, a hysterectomy, no kids and I had to listen to this woman talking to her endless stream of visitors congratulating her. It was not a good fit. I felt like complaining but didn’t. It didn’t help my recovery.

The substantial pressure on bed access across the hospital system may present particular challenges for women with gynaecological cancer. While some women are treated within specialist gynaecological cancer units, other women are treated within general ward and ambulatory environments with less experienced staff and different patient populations, including men and pregnant or post-natal women.

The consumer survey undertaken to inform the National Framework indicated that the majority of women (76%, n=24) were treated as inpatients within a woman-only environment. Of these, three women were treated in a ward that included maternity patients. Eight women (24%) reported being treated in a mixed-gender environment.

There was evidence from one service of women with gynaecological cancer being successfully managed in the same environment as women with complex pregnancies. This avoided women being co-located in a mixed-gender ward. The critical success factors in this co-location included:
- a proactive approach to the service integration prior to the co-location
- women are co-located on the same floor but not in the same rooms
- while there is some sharing of staff, each patient group has its own staff
- proactive preparation of women for the ward environment
- optimising skill sharing across the different nursing groups.

However, other consumers and service providers expressed strong views that being cared for with maternity patients was very confronting to women whose treatment has resulted in infertility.

From these stakeholders’ perspectives, women should be nursed:
- within a woman-only environment
- in an environment that was not co-located with maternity services
- within a consistent inpatient facility to optimise the development of clinical expertise of generalist service providers, e.g. nursing staff.

Given the sensitive nature of gynaecological cancer, services need to respond to all women in a way that is respectful of their diverse cultural, social and linguistic needs and ensures appropriate privacy and support.

Services need to adhere to the relevant national and state or territory policies that address the specific needs of Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse communities. Where the service population includes significant numbers of women with more complex cultural or other needs, additional resources may be needed.

Because of cultural beliefs, past experiences or personal preferences, for some women access to female service providers (and related staff) is essential to facilitate optimal care. Services need to accommodate these needs wherever possible, and where not possible, need to have a range of strategies to support women.

Finally an optimal physical and cultural environment will do much to create a safe emotional environment for women. This will be further enhanced by the skills of staff to appropriately respond to women’s emotional concerns (see also Service Delivery Element 6).

Service delivery components
The following outlines key service delivery components to facilitate access to a woman-centred environment and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>The physical environment</td>
<td></td>
</tr>
<tr>
<td>• Strategies should be in place to ensure all women are cared for within a woman-only environment.</td>
<td></td>
</tr>
<tr>
<td>• Within non-specialist gynaecological cancer services, women should be treated within a consistent inpatient environment to optimise the development of clinical expertise within generalist service providers, e.g. nursing staff.</td>
<td></td>
</tr>
<tr>
<td>• Private space is available for complex and sensitive consultations.</td>
<td></td>
</tr>
<tr>
<td>• Where women are nursed in a sub-optimal environment:</td>
<td></td>
</tr>
<tr>
<td>- strategies are put in place to proactively address this</td>
<td></td>
</tr>
<tr>
<td>- specific feedback on women’s experiences is obtained to guide the impact of these strategies.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The cultural and emotional environment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• If not part of overall organisational policies, strategies are in place to readily identify Aboriginal and Torres Strait Islander women and women from CALD backgrounds to optimise culturally appropriate care.</td>
<td></td>
</tr>
<tr>
<td>• Staff have resources and cultural competencies to assess and respond to the diverse needs of women with gynaecological cancer.</td>
<td></td>
</tr>
<tr>
<td>• Services work in partnership with internal and community-based Aboriginal health and community workers to support Aboriginal and Torres Strait Islander women across the care pathway.</td>
<td></td>
</tr>
<tr>
<td>• Trained interpreters are always used to facilitate communication at critical pathway points for women whose first language is other than English.</td>
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</tr>
<tr>
<td>• All service providers and associated staff (such as clerical staff) have good communication skills appropriate to their role to respond sensitively to the needs of women (see also Service Delivery Element 6).</td>
<td></td>
</tr>
</tbody>
</table>

Access to female service providers including clinical and non-clinical providers, e.g. interpreters
Services have strategies in place to:
- ensure services are aware of and sensitive to cultural preferences of women
- optimise women’s access to female service providers where possible including offering referral to other services
- provide optimal support and sensitive care to women when a female provider is not available.
Appendix F

6. Supportive care

Objective

All women have access to supportive care that facilitates informed decision-making and coping across the care pathway and includes a focus on information, physical, social, practical, psychological, psychosexual and spiritual needs.

Rationale

“I was encouraged to seek further information and support but was not given directions on where to go to find it. It felt overwhelming and was difficult to wade through what was helpful and accurate and what was not.”

Supportive care is a core component of cancer service delivery and is defined as care that:

- helps the patient and their family to cope with cancer and treatment of it— from pre-diagnosis, through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement.
- aids the patient to maximise the benefit of treatment and to live as well as possible with the effects of the disease.115

Supportive care covers the following five domains of need that are of equal importance:

- physical
- social including practical
- psychological including psychosexual
- spiritual
- information.

The range of women’s needs across these domains is highlighted on page 9 and Appendix E. Evidence in the literature also highlights:

- that specific factors such as poor social support and previous experience of anxiety and depression may increase the risk of psychosexual distress in the future116
- a significant minority of women will experience ongoing emotional distress117
- the role of community support services to respond to the unmet supportive care needs of survivors118

- poorly addressed short- or long-term physical symptoms such as fertility and lymphoedema impact significantly on emotional distress114
- the prevalence of psychosexual concerns116
- the value of social and peer support for all people affected by cancer121
- the role and value of good information provision and service provider communication.

Given diverse supportive care needs among cancer patients, there is an increasing emphasis on a tiered approach to supportive care whereby all patients gain access to a base level of service. Depending on different levels of need, more complex and specialist interventions are needed for increasingly smaller groups of patients112 (see Figure 4). There is increasing emphasis on routine ‘screening’ for supportive care needs using specific screening tools at key pathway points.122 The Victorian Supportive Care Policy and UK recommendations indicate that screening should take place at key pathway points112 and involves:

- the use of a screening tool (preferably self-administered) and a clinical discussion
- prioritising needs based on the five domains of care
- providing an immediate response
- implementing appropriate support, referral and follow-up.

However, there is more limited evidence about how best to introduce it effectively into routine practice with different approaches currently being taken in different jurisdictions.

Supportive care may be provided by:

- generalist providers such as medical and nursing staff as part of their broader practice
- specialist supportive care providers with specialist knowledge in working with women with gynaecological cancer
- specialist supportive care providers who work with more general client populations.

Consultation identified significant variability in the provision of supportive care including:

- specialist centres tend to have better access to a range of specialist supportive care providers and services including social workers and psychologists
- more limited attention paid to supportive care needs within other service approaches
- limited evidence of routine supportive care screening
- the need for an early consultation that addresses women’s information needs and emotional concerns, prepares them for the impact of treatment and encourages resilience and confidence to cope
- peer support programs and ‘wellness and information’ services were available within a number of specialist centres or within the community

Service delivery components

The following outlines key service delivery components to facilitate access to supportive care and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
</table>
| Screening for supportive care needs at key points in the service pathway | - There are agreed protocols for trialling screening of women’s risk of psychosexual distress and current supportive care and psychosexual needs using an agreed screening tool and at agreed points in the pathway.  
  - Based on the evidence of the above trials, screening is implemented into routine practice.  
| Responding to supportive care needs including: | - All women are provided with information in appropriate formats about:  
  - their specific diagnosis, treatment options and final treatment plan  
  - internal and external supportive care services including peer support programs.  
  - Service providers have the skills to respond to the range of supportive care needs appropriate to their scope of practice that build on women’s skills and encourage resilience.  
  - Services have clear pathways and access to service directories to facilitate referral to supportive care providers within their service or the community.  
  - Strategies are in place to optimise women’s access to peer support through internal and community-based programs.  
  - information needs  
  - specific physical needs such as fertility, menopausal issues, pain management, lymphoedema, continence issues  
  - social and practical needs  
  - emotional and psychological distress  
  - psychosexual needs |
Service delivery component | Supporting systems and processes
---|---
Addressing the supportive care needs of women from diverse backgrounds including the provision of information resources that take into consideration the cultural, language and literacy needs of individual women | • Strategies are in place to identify and address the individual support and information needs of women from regional and remote Australia, Aboriginal and Torres Strait Islander women, women from CALD backgrounds and others with special needs.
• Partnerships are developed with relevant internal services and with external service providers and communities to support the needs of women from diverse backgrounds.

Strengthening service providers’ capacity to identify and respond appropriately to women’s supportive care needs within their scope of practice | • All general health service staff such as administrative personnel have good communication skills to optimise women’s experience of the health service.
• All service providers have good communication skills to identify supportive care needs, respond appropriately and to facilitate referral to appropriate supportive care services.
• Service providers have high-level communication skills appropriate to their role to facilitate:
  – breaking bad news
  – responding to emotional cues
  – initiating discussion about psychosocial issues
  – transition to palliative care.
• Strategies are in place to facilitate secondary consultation between different specialist supportive care providers and other personnel working with women with gynaecological cancer.

7. Coordinated care

Objective
Women should experience their care as streamlined, timely, efficient and well-coordinated across the continuum of care.

Rationale
‘Successful cancer care is not only about the survival and morbidity… but also relates to the experience of the person with cancer... what the treatment process is like’.1,2,3

Cancer care for all cancer patients requires access to multiple providers across services and time to meet their clinical needs. Poorly coordinated care:
• increases distress and financial burden for cancer patients and their families;4,5
  – distress may be further compounded for people from regional and rural Australia who have to access metropolitan services for cancer care;6
• creates additional burden on service providers and the service system overall.5,7

However, Australia’s complex and fragmented healthcare system and the limited electronic health information systems currently constrain more system-wide approaches.1,7 Key approaches to optimising well-coordinated care across services and sectors include:

Optimising information flow through electronic information transfer, enhanced documentation, documented communication between providers and patient-held records.

Effective organisational structures or approaches that optimise teamwork and communication including shared management protocols, individualised care plans, multi-and interdisciplinary meetings, clear referral protocols and processes to improve access into and out of services and sectors.

A key contact who is readily accessible to the patient and will facilitate coordination of care and assist the patient to navigate complex systems. Increasing evidence highlights the value of a ‘system navigator’ or ‘care coordinator’ role for cancer patients overall as well as supporting disadvantaged groups.8,9

The GP also has an important role in coordinating care particularly for regional and rural women, once they have completed treatment and if their disease progresses.

UK guidance indicates that the woman’s GP should be informed of the diagnosis by the end of the following working day after the woman has been told.10 Evidence from the consultation with stakeholders and consumers indicated variation in current practices to optimise well-coordinated care including:

• 59% of consumers who completed an electronic survey rated coordination of their care as being good or very good and 28% rated it as poor or very poor
• poorer communication with local service providers on discharge resulting in significant problems and distress for individual women, particularly those in regional Australia11
• many specialist gynaecological cancer centres appeared to have a range of strategies to optimise care coordination including multidisciplinary meetings, referral pathways and access to a specialist gynaecological nurse consultant/coordinator
• nurse consultant/coordinator roles were varied with part of the role including:
  – being a key contact role for women and/or external service providers
  – assisting in care coordination and helping women to navigate the system
  – liaison with regional cancer care coordinators to optimise regional women’s access to local services that has improved patients’ experiences and streamlined care.12
• some evidence of good communication with regional providers to optimise local care
• broader system issues make care coordination difficult and may be exacerbated in particular situations, e.g. providing concurrent chemotherapy and radiotherapy when the two treatment modalities are provided in geographically separated settings
• in non-specialist service settings, there may be a greater reliance on informal communication between providers and other individual clinicians.
Appendix F

Service delivery components
The following outlines key service delivery components to facilitate coordinated care and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
</table>
| Optimising information flow between service providers | • Basic systems and processes should be in place to ensure:  
  - good documentation of agreed treatment plans  
  - timely information flow to other service providers  
  - timely communication with the woman’s GP at agreed times including on diagnosis, inpatient discharge, treatment completion, recurrence and advanced disease  
  - appointments are proactively made with local providers especially for women returning to regional/rural areas.  
  • Mechanisms are in place to ensure women are provided with their own information and treatment plans. |

| Organisational approaches to coordinating care within and between services and sectors including: | A range of strategies should be in place to optimise team communication including multidisciplinary team planning meetings and/or management protocols.  
• Clear referral pathways and criteria support women’s referral into specialist services and across services and sectors.  
• Organisational approaches are in place to optimise well-coordinated care and may include:  
  - links with regional cancer service providers to optimise local clinical care where possible  
  - good links and information flow between different treatment providers within and between services  
  - service directories of community organisations to optimise women’s access to local support services  
  - approaches to liaise with internal and external Aboriginal health and community workers to coordinate care  
  - addressing structural issues to ensure women can receive concurrent therapy at the same service site. |

| Access to key contact and coordinating roles | A nurse consultant or other nominated coordinating role is identified and available as a key contact for all women across the care pathway (or at different points) to help women navigate the system and be a contact point for external providers.  
• Priority is given to optimise care coordination for regional and rural women and women that require additional support because of specific needs such as cultural, linguistic, socioeconomic, low literacy or disability needs. |

8. Continuous quality improvement, consumer feedback, clinical trials and research

**Objective**

All services providing care for women with gynaecological cancer are active participants in continuous quality improvement (including audit), consumer feedback strategies, clinical trials and research to improve outcomes for women.

**Rationale**

The management of and outcomes for women will be optimised in an environment and culture that encourages continuous quality improvement, clinical trials and research, including regular monitoring and reporting of key outcomes.

In addition, with the strong focus on patient-centred care, there are health policy requirements for service improvements to be informed by consumer feedback and that consumers should be actively in service development. The electronic consumer survey undertaken to inform the development of the National Framework demonstrates the value of women’s feedback and gaining their experiences to optimise care (see Appendix D).

Finally a strong research commitment and culture creates an environment that is attractive to the future workforce. Evidence from stakeholder consultation highlighted:

• a range of clinical, nursing and supportive care research in some settings  
• limited evidence to assess the outcomes of variance in practices across services that could guide future service directions

• the role of the Australia New Zealand Gynaecological Oncology Group (ANZGOG) and other research organisations such as the Trans-Tasman Radiation Oncology Group (TROG) in facilitating clinical trial participation and research  
• some resources have been made available through Cancer Australia and some jurisdictions to support clinical trial and research infrastructure  
• quality assurance, clinical trial and research activities at a national and service level are significantly constrained by:  
  - the lack of resources to support the data collection, analysis and reporting  
  - lack of clear performance measures against which to monitor service performance and outcomes  
• the need for a national database of relevant clinical trials  
• difficulty in access to clinical trials for women in smaller and regional services.

A minimum dataset for the three major gynaecological cancers has recently been developed12 and is currently being trialled. This database will:

• assist in national consistency in defining, recording an monitoring information about patients with ovarian, endometrial and cervical cancer  
• enable geographic comparisons and benchmarking in relation to cancer stage and diagnosis, prognostic indicators and survival for stage-specific categories  
• assist in improving patient outcomes through a national approach informing planning, quality improvement and evaluation strategies for cancer services.13,14
Appendix F

Service delivery components
The following outlines key service delivery components to facilitate continuous quality improvement, consumer feedback, clinical trials and research and the supporting systems and processes that may be required to achieve them.

<table>
<thead>
<tr>
<th>Service delivery component</th>
<th>Supporting systems and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuous quality improvement</td>
<td>All relevant professional disciplines who provide gynaecological cancer or related services participate in the audit requirements of their professional bodies.</td>
</tr>
<tr>
<td>Consumer feedback to inform service improvement</td>
<td>A range of strategies are in place to:</td>
</tr>
<tr>
<td>Clinical trials available and uptake encouraged</td>
<td>Strategies are in place to:</td>
</tr>
<tr>
<td>Research capacity to guide clinical management and service improvement</td>
<td>All services are informed by and actively contribute to clinical research (including acute management, managing symptoms in all disease phases, palliation and quality of life research) and/or health service research.</td>
</tr>
</tbody>
</table>

Advantages and disadvantages of different service models (cont’d page 100)

<table>
<thead>
<tr>
<th>Service model</th>
<th>Specialist centre model</th>
<th>Visiting specialist model</th>
<th>Shared care model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advantages</td>
<td>• Provides good access to women who live locally.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Access to high-quality multidisciplinary care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Provides a critical mass to build and consolidate expertise in all providers.</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>• Optimal access to clinical trials and research.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Optimises sub-specialty training.</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>• Better able to match skills to need.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Better able to support generalist providers.</td>
<td></td>
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<tr>
<td></td>
<td>• Facilitates more local access to specialist surgical or other skills for some women.</td>
<td></td>
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<tr>
<td></td>
<td>• May enable women to have all treatment in a local service depending on access to other treatment modalities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Builds and develops relationships between providers and enhances information flow and skills development.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Multidisciplinary care planning may be through local teams or linkage with specialist centres.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Facilitates additional training opportunities for larger cohorts of general gynaecology trainees that may optimise future assessment and referral of women with gynaecological cancer.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• Facilitates skill development for a range of associated service providers, e.g. local pathologists.</td>
<td></td>
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<tr>
<td></td>
<td>• Relieves pressure on beds and other facilities within specialist centres.</td>
<td></td>
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<tr>
<td></td>
<td>• Enables women to access some care locally.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Builds and develops relationships between providers and enhances information flow and skills development.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[ BACK TO CONTENTS ]
Appendix G

<table>
<thead>
<tr>
<th>Service model</th>
<th>Specialist centre model</th>
<th>Visiting specialist model</th>
<th>Shared care model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disadvantages</td>
<td>Significant access challenges for women from regional and remote areas.</td>
<td>Travel time for visiting specialists.</td>
<td>Needs optimal information flow and clear guidance between services.</td>
</tr>
<tr>
<td></td>
<td>May result in deskilling of some generalist providers.</td>
<td>Variable access to multidisciplinary processes.</td>
<td>Women may get “lost” between providers.</td>
</tr>
<tr>
<td></td>
<td>If future models rely on specialist centres only, increasing bed and service demand will be placed on these centres and their associated health services.</td>
<td>Care dependent on local specialist interest in supporting a visiting service and/or the visiting specialist’s commitment.</td>
<td>Limited access to clinical trials or other research.</td>
</tr>
<tr>
<td></td>
<td>Secondary consultation such as review of pathology slides from generalist providers may result in a significant additional burden on specialist staff.</td>
<td>Depending on service volume, availability of training and other service demands, it may be difficult to build up local expertise of other service providers.</td>
<td></td>
</tr>
</tbody>
</table>

Appendix H

Summary of service mapping findings

Introduction
In order to capture a profile of the resources and practices of all the major gynaecological cancer services across Australia, a service mapping tool was developed and implemented through the related NCIC jurisdictional projects.

In addition, it was envisaged that through this data the project team would gain an understanding of the current service-volume and resources available (i.e. EFT workloads). This data would provide some guidance for developing future resource requirements.

Method
The service mapping tool aimed to access a wide range of information as outlined in Table H.1. The tool was initially drafted and feedback sought from key stakeholders involved in the jurisdictional projects.

The finalised tool was forwarded to all staff in the jurisdictional projects to complete for each major gynaecological cancer service within their jurisdiction. This data would then complement information gathered through the project consultation.

Limitations
A number of factors influenced the data collection including:
- Its timely collection was constrained by the later appointment of jurisdictional project staff in some states to facilitate data collection and the general busyness of service staff to complete the tool.

Table H.1: Summary of content of the service mapping tool

<table>
<thead>
<tr>
<th>Category</th>
<th>Description of question topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service profile</td>
<td>State/territory, and whether a metropolitan or regional service</td>
</tr>
<tr>
<td></td>
<td>Number and profile of newly diagnosed women per annum</td>
</tr>
<tr>
<td>Finding cancer early</td>
<td>Referral sources</td>
</tr>
<tr>
<td></td>
<td>Referral catchments</td>
</tr>
<tr>
<td></td>
<td>Management of women with abnormal Pap tests</td>
</tr>
<tr>
<td>Managing and supporting women with cancer</td>
<td>The multidisciplinary team and team practices</td>
</tr>
<tr>
<td></td>
<td>Profile of women discussed in multidisciplinary planning processes</td>
</tr>
<tr>
<td></td>
<td>Supportive care screening and multidisciplinary meetings</td>
</tr>
<tr>
<td></td>
<td>Research</td>
</tr>
<tr>
<td></td>
<td>Current service networks</td>
</tr>
<tr>
<td></td>
<td>Managing women from diverse backgrounds</td>
</tr>
<tr>
<td>Follow-up and related care</td>
<td>Availability of written protocols</td>
</tr>
<tr>
<td></td>
<td>Referral back to other providers for follow-up care</td>
</tr>
<tr>
<td></td>
<td>Range of services available</td>
</tr>
<tr>
<td>End-of-life care</td>
<td>Access to in-house and external community-based services</td>
</tr>
<tr>
<td></td>
<td>Critical issues</td>
</tr>
<tr>
<td>Professional development</td>
<td>Current certified gynaecological oncologist trainees</td>
</tr>
<tr>
<td></td>
<td>Other staff development activities and needs</td>
</tr>
</tbody>
</table>
Appendix H

• variability in how some items were reported, e.g. the survey requested information about the numbers and EFT, or number of sessions, of specific service providers but this data was either unknown or inconsistently completed
• given local organisational arrangements of services in some jurisdictions (e.g. centralised multidisciplinary processes or one or more major providers working across different public and private services), some data was provided for the whole jurisdiction. It was more difficult to tease out some aspects of the data as they related to specific services within the jurisdiction
• the data only reflects current practice within major gynaecological cancer services but has not been collected on smaller metropolitan or regional services which may be providing at least some aspects of gynaecological cancer care.

Given these factors, the data has been used carefully to inform the development of the National Framework. It does, however, provide some additional broad evidence of current practices that may be useful to guide the implementation of the jurisdictional projects.

In addition, using the service mapping tool (in its current form or with modifications) may enable jurisdictional project staff to map resources and practices in smaller metropolitan or regional gynaecological cancer services.

Results

Twelve completed service mapping tools were received. Of these:
• three were completed as ‘whole of state’ tools
• nine were completed by individual services.

Data was not received from three known specialist gynaecological cancer centres in two states. In one state, this appeared to be related to the specific geographic scope of their jurisdictional project.

Six services were described as metropolitan services, five as metropolitan and regional services and one as a regional service. Where data is available on individual services, the number of new patients seen per annum ranged from 98 to 250, with all respondents indicating that they managed women with the full range of gynaecological cancers.

1. Finding cancer early—referral pathways

Not surprisingly, all services indicated that they received many referrals from gynaecologists and many or some referrals from GPs, with many of these referrals being for women living in the immediate catchment area (see Table H.2).

Eight service respondents indicated that they provided a diagnostic/management service for all women with cervical abnormalities. Gynaecological oncologists were part of the colposcopy service team in five of these services.

Four services indicated that they only provided a ‘triage’ service for women:
• requesting a second opinion
• with high-grade squamous abnormalities
• with glandular abnormalities.

Table H.3: Service volume and discipline-specific resources

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of new patients per annum</th>
<th>CCG(1)</th>
<th>General gynaecologist</th>
<th>Radiation oncologist</th>
<th>Medical oncologist</th>
<th>Pathologist</th>
<th>Specialist gynaecological cancer nurse</th>
<th>Social worker</th>
<th>Psychologist</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 High volume(1)</td>
<td>2 2 5 1 1</td>
<td>1 EFT</td>
<td>As needed</td>
<td>Nil</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>98 1 2 4 1</td>
<td>1 EFT</td>
<td>0.1 EFT</td>
<td>0.5 EFT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>138 3 2 2 2</td>
<td>1 EFT</td>
<td>0.5 EFT</td>
<td>0.5 EFT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>155 3 2 2 2</td>
<td>1 EFT</td>
<td>Part-time</td>
<td>As needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>99(2) 1 2 3 2</td>
<td>1 EFT</td>
<td>0.4 EFT</td>
<td>As needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>&lt;400(2) 4 2 2 2</td>
<td>1 EFT</td>
<td>1 EFT</td>
<td>Part-time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>250 4 2 2 2</td>
<td>1 EFT</td>
<td>0.5 EFT</td>
<td>0.8 EFT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>185 4 2 2 1</td>
<td>1 EFT</td>
<td>As needed</td>
<td>As needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>800-850(2) 5 0 2 2 5</td>
<td>1 EFT(3)</td>
<td>1 EFT(3)</td>
<td>1 EFT(3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>163 1 2 1</td>
<td>1 Nil</td>
<td>As needed</td>
<td>As needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>191 3 0 1 1</td>
<td>1 EFT</td>
<td>1 EFT</td>
<td>0.8 EFT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>220 2 0 3 1 4</td>
<td>0.9</td>
<td>As needed</td>
<td>As needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Data provided for total number of all patients per annum, not new patients
2. Service data provided for whole of state rather than individual services.
3. Based on the resources within one public service within this state that managed 210 new patients per annum.
4. Certified gynaecological oncologist

2. The multidisciplinary team

Table H.3 provides an overview of the services, service volume and the numbers (or EFT) of staff by discipline.

As we have variable data for exact EFT for the medical providers, caution must be used in interpreting the above data. However, from the available data, we can see that a small number of services have solo providers for gynaecological oncologists, radiation oncologists and/or medical oncologists. While the EFT allocation of these single providers may be sufficient to manage current service demand, there may be challenges in terms of planned and unplanned leave coverage and succession planning.

Table H.2: Referral providers and catchments

<table>
<thead>
<tr>
<th>Referral source</th>
<th>Number of services indicating frequency of referral</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Many</td>
</tr>
<tr>
<td>Referral provider</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>7</td>
</tr>
<tr>
<td>Gynaecologist</td>
<td>12</td>
</tr>
<tr>
<td>General surgeon/physician</td>
<td>8</td>
</tr>
<tr>
<td>Women’s health services</td>
<td>4</td>
</tr>
<tr>
<td>Emergency department</td>
<td>6</td>
</tr>
<tr>
<td>Referral catchment</td>
<td></td>
</tr>
<tr>
<td>Immediate catchment</td>
<td>11</td>
</tr>
<tr>
<td>Other metropolitan areas</td>
<td>3</td>
</tr>
<tr>
<td>Other metropolitan areas</td>
<td>5</td>
</tr>
<tr>
<td>Regional areas</td>
<td>7</td>
</tr>
<tr>
<td>Rural/remote areas</td>
<td>5</td>
</tr>
<tr>
<td>Interstate</td>
<td>2</td>
</tr>
<tr>
<td>Other/International</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix H

The following additional resources were also available as part of the multidisciplinary team:

- All services indicated that they had access to a palliative care physician.
- Seven services indicated that they also had access to a palliative care nurse consultant.
- Six services indicated that they had data management resources with these resources ranging from 0.1 to 1.5 FPT.

3. Multidisciplinary team planning participation and processes

All 12 respondents indicated that they held multidisciplinary treatment planning meetings. Three services indicated that they currently did or were commencing to use the relevant MBS item number to support multidisciplinary team participation.

Table H.4 summarises the reported attendance of different multidisciplinary team members across the 12 services. The major treating clinicians, pathologists and specialist gynaecological cancer nurses were mostly reported as always or mostly attending the meetings. Other providers such as social workers or psychologists attended less frequently. This may be in part due to the variable level of resources within their service or other factors influencing participation.

Eleven services indicated that all women were informed that their case would be discussed at the multidisciplinary meeting. For two services consent was provided formally and for seven services, consent was provided informally; two services did not respond.

Table H.5 highlights some variation in the women discussed within the multidisciplinary meeting and summarises other multidisciplinary and supportive care processes with this.

Variation in services included:

- Few services reported giving women a written copy of their treatment plan.
- There was limited use of a formal supportive case screening tool.
- Five of the 12 services reported holding specific multidisciplinary supportive care/psychosocial care meetings.

Services reported the following range of research activities:

- 12 services reported participation in clinical trials.
- Nine services reported participation in nursing research.
- Seven services participated in supportive care/psychosocial research.
- Six services participated in basic research.

4. Organisational or network arrangements

Ten services reported a range of formal or informal organisational arrangements between services, with seven indicating that these arrangements were formalised. In addition to organisational arrangements with intrastate services, four services indicated service arrangements for managing interstate women.

---

Table H.4: Reported frequency of attendance at multidisciplinary meetings across services

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Frequency of reported attendance across services</th>
<th>Always</th>
<th>Mostly</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not applicable/no response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead certified gynaecological oncologist</td>
<td></td>
<td>9</td>
<td>1</td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Other gynaecological oncologists</td>
<td></td>
<td>8</td>
<td></td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General gynaecologist</td>
<td></td>
<td>1</td>
<td>3</td>
<td></td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td></td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Medical oncologist</td>
<td></td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Pathologist</td>
<td></td>
<td>11</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Specialist gynaecological nurse</td>
<td></td>
<td>8</td>
<td>2</td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Palliative care physician</td>
<td></td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Palliative care nurse</td>
<td></td>
<td>2</td>
<td>5</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data manager</td>
<td></td>
<td>3</td>
<td>1</td>
<td></td>
<td>6</td>
<td>2</td>
</tr>
</tbody>
</table>

Table H.5: Number of services reporting frequency of multidisciplinary activities and supportive care practices

<table>
<thead>
<tr>
<th>Frequency of multidisciplinary discussion for different patient groups</th>
<th>Always</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newly diagnosed women</td>
<td>9</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Women with recurrence</td>
<td>8</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Women in palliative care</td>
<td>3</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Private patients of team members</td>
<td>6</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Multidisciplinary processes</th>
<th>Always</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consideration of psychosocial issues in multidisciplinary meeting</td>
<td>9</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Agreed treatment plan documented in medical record</td>
<td>9</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Copy of written treatment plan given to woman</td>
<td>1</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Copy of written treatment plan sent to GP</td>
<td>8</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supportive care</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive care screening tool used</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Psychosocial/supportive care multidisciplinary meeting held</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Minimum core set of information resources given</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>
The range of activities highlighted included:

- referral in from specific regional services
- the provision of outreach clinics of varying frequency
- joint multidisciplinary meetings using videoconferencing technology (for one service this was undertaken regularly whereas for a second service this was occasionally done)
- one-on-one consultations between individual providers.

Six services indicated that they had formal or informal organisational arrangements with related private services. These included:

- private patients being discussed in a common multidisciplinary meeting
- nurse coordinators providing support to women in the private sector as well as public sector patients (this was a formalised arrangement in at least one service).

5. Specific client groups
All 12 services indicated that they provided care to Aboriginal and Torres Strait Islander women with gynaecological cancer but the numbers seen per year were small:

- only two services indicated that they saw more than 20 Aboriginal and Torres Strait Islander women per year
- five services saw between six and 20 Aboriginal and Torres Strait Islander women per year
- four services saw fewer than five women per year and one service was unsure of numbers.

Six services indicated that they provided care to women from CALD backgrounds with:

- one service indicating that they saw over 100 CALD women per year
- three services indicated that they saw between 30 and 50 CALD women per year
- one service indicated that CALD women would represent approximately 10% of their population
- one service indicated that they had no mechanism to identify CALD women.

6. Follow-up care
Seven services indicated that they had formal written guidelines for the follow-up management of women. Eleven services indicated some shared care follow-up arrangements but their qualitative feedback indicated that this occurred sporadically, more often for regional or rural women and/or at least five years after diagnosis and treatment.

The following services to support women’s ongoing care were identified and available either as part of the service team, or were available through other services on- or off-site:

- psychology
- lymphoedema services
- sexual counselling
- fertility services
- continence services
- genetic counselling.

Other services identified included access to pain management services, menopause clinics, community palliative care and pharmacy services.

While all the above service providers were available, respondents indicated that timely access was problematic for at least some providers.

7. End-of-life care
All 12 services indicated that they had access to palliative care medical and/or nursing consultants on site. These providers offered:

- a range of support to women
- advice, guidance and support to the gynaecological cancer service team
- liaison with relevant inpatient and community-based palliative care services.

Eight services indicated that women in the palliative care phase were discussed in the multidisciplinary meeting although in some circumstances this may only be:

- if additional active treatment was required
- in the context of an inpatient multidisciplinary team meeting.

The lack of specialist palliative care services was highlighted by a number of respondents.

8. Professional development
Six services indicated that they currently had a gynaecological oncologist trainee and that this program was well organised.

A range of other formal and informal training programs were available for other staff particularly nursing staff.

Key issues identified included:

- challenges in general gynaecology registrar training
- the need for stronger training and education for ward nursing staff
- and for nurses working in regional and community-based services
- the need to develop nurse practitioner roles
- time and resources were significant barriers to strengthening nursing skills.

Conclusions
These service mapping findings provide a broad overview of the range of services and practices available in 12 specialist gynaecological services across Australia.

The findings have been used to appropriately inform the National Framework. In addition, while the findings should be used cautiously because of their limitations, they may provide a benchmark or some guidance for the developing jurisdictional projects.