



**NATIONAL BREAST
CANCER CENTRE**

Incorporating the
Ovarian Cancer Program

Priority actions for ovarian cancer control:

a framework for a
national approach.

April 2002

Foreword

Ovarian cancer is the leading cause of death from gynaecological cancers in Australia. Health care professionals and consumers have identified a number of opportunities for improvement in ovarian cancer control.

Priority actions for ovarian cancer control: a framework for a national approach was developed by the National Breast Cancer Centre following an extensive process of consultation with over 50 key stakeholders across Australia. It identifies a number of priority actions which are seen as being important for ovarian cancer control. This document is presented as a national framework for all individuals and organisations working to improve outcomes for women in Australia with ovarian cancer.

Initiatives to be undertaken by the National Breast Cancer Centre to improve ovarian cancer outcomes are detailed in the document, *Ovarian Cancer Program*, available from the Centre.

Part I - Background

Ovarian cancer is the leading cause of death from gynaecological cancers in women in Australia. In 1998, 1216 women in Australia were diagnosed with ovarian cancer and 769 women died from the disease.¹ Cancer of the ovary was the eighth most common cancer and the sixth most common cause of death from cancer in women in 1998.¹ The median age for diagnosis of ovarian cancer is 64 and the incidence increases with age.² The risk of developing ovarian cancer before the age of 75 is 1 in 103.²

The incidence of ovarian cancer has changed little between 1983 and 1998, and has been steady since 1990. Mortality was reasonably stable from 1983 to 1993 and then fell slightly by 1.4% a year from 1993 to 1998.¹

The outcomes for women diagnosed with ovarian cancer are often poor. Seventy percent of ovarian cancers are advanced at time of diagnosis and only about 42% of women with ovarian cancer will survive five years or more from diagnosis.³ Survival is best in the younger age groups of women and falls with increasing age. Poor survival rates are likely to be related to the high proportion of women who have advanced disease at the time of diagnosis.⁴ At present, there is no known effective method for early diagnosis.

There are several types of ovarian cancer dependent upon tumour origin: epithelial, sex cord stromal or germ cell. Epithelial ovarian cancers arise in the cells covering the ovary and are the most common type of ovarian cancer. Germ cell and sex cord stromal cell ovarian cancers are rare. For the purposes of this document, ovarian cancer is defined as including all types irrespective of tumour origin.

One group of epithelial cancers, not as aggressive as others, is described as having 'low malignant potential' (LMP). LMP tumours occur at younger ages and with a more favourable stage distribution and prognosis than other ovarian cancers. Different countries at different times have included LMP tumours in their incidence and survival data. In Australia, most cancer registries exclude these cancers – although LMP tumours are included in Victoria cancer registry data. As a result, incidence and survival will be higher in countries and cancer registries that do include these LMP cancers than they are in Australia.

The direct health care costs of malignant ovarian cancers were \$13.5 million in the 1993/94 financial year. Hospital costs were by far the greatest proportion (87%) of the direct costs of ovarian cancer in 1993/1994.⁵ Ovarian cancer is estimated as the fourteenth most costly cancer to treat with an estimated lifetime cost of nearly \$13,000 per new case.⁵

Health care professionals and consumers have identified a number of opportunities for improvement in ovarian cancer control. Consumer groups and health care professionals are concerned about the current level of awareness of ovarian cancer, delayed or inappropriate referral, inadequate pre-operative assessment, incomplete staging, lack of multidisciplinary teams, and lack of support and palliative care.⁶

Part 2 – The development of priority actions

In September 2001, a workshop entitled *Improving outcomes for Australian women with ovarian cancer* was held as a collaborative initiative of the National Cancer Control Initiative, the Commonwealth Department of Health and Aged Care, OvCa Australia and the National Breast Cancer Centre. The workshop was attended by consumer advocates, epidemiologists, gynaecological oncologists, medical oncologists, clinical researchers, and representatives of state and federal government and cancer organisations. The workshop identified a number of opportunities for improving outcomes for women with ovarian cancer (Appendix A).

At the September workshop, the Commonwealth Government announced that it would provide funding to the National Breast Cancer Centre (the Centre) to implement an ovarian cancer initiative. The funding of \$500,000 over two years will enable the Centre to implement a program that will improve outcomes for women with ovarian cancer.

In November 2001, the Centre convened an Interim Ovarian Cancer Steering Group to identify priority actions to improve control of ovarian cancer. Members of the Interim Steering Group are listed in Appendix B. The Interim Steering Group developed a document summarising the priority actions to improve the control of ovarian cancer in Australia. While some of these priority actions will be undertaken by the National Breast Cancer Centre's two year Ovarian Cancer Program, it is hoped that this document will also form a basis for all groups working to improve ovarian cancer outcomes.

A nominal group process was used to provide a semi-structured approach to seeking consensus among the Steering Group members about the priorities. Twenty priorities in ovarian cancer were identified by the Steering Group and subsequently circulated to key stakeholders for input. At a second meeting in January 2002, the Steering Group considered the first draft of the priority actions and comments received about the list of priorities from stakeholders (Appendix C). The priority actions were agreed at a third and final meeting of the Interim Ovarian Cancer Steering Group convened in February 2002.

Part 3 – Objectives and priority actions

Objectives and priority actions identified as important following consultation with stakeholders are detailed below. (*Please note:* The order in which the Objectives are presented does not represent an order of priority).

OBJECTIVE I

To identify and provide accurate information about prevention and risk factors for ovarian cancer

While much research in Australia and internationally is directed at understanding the causes of ovarian cancer, there are currently no opportunities for community-wide prevention programs. Known risk factors include family history,⁴ age² and previous personal history of ovarian cancer. Pregnancy and oral contraceptive use are associated with a reduced risk of ovarian cancer.⁷ Prophylactic oophorectomy, tubal sterilisation and hysterectomy may reduce a woman's risk of ovarian cancer.

Priority actions:

- 1.1 To monitor research about risk factors and opportunities for prevention for ovarian cancer
- 1.2 To disseminate accurate information about risk factors and prevention for ovarian cancer to health care professionals and the community

OBJECTIVE 2

To provide accurate information and encourage appropriate service provision for women with a strong family risk or known genetic risk of ovarian cancer.

Hereditary factors appear to account for about 3-10% of cases of ovarian cancer.^{4,8} Women with a genetic mutation in BRCA1 and BRCA2 have a risk of between 10% - 60% of developing ovarian cancer by the age of 75. Women identified as being at high risk of ovarian cancer may benefit from referral to genetic clinics.

Priority actions:

- 2.1 To revise the guidelines for general practitioners – *Advice about familial aspects of breast cancer and ovarian cancer: a guide for health professionals*
- 2.2 To develop a brief questionnaire to identify women at high risk of ovarian cancer based on their family history
- 2.3 To ensure that women at high risk of ovarian cancer based on their family history receive appropriate information, surveillance, treatment and support

OBJECTIVE 3

To improve the detection of ovarian cancer

It is estimated that about 70% of ovarian cancers are advanced at diagnosis;⁴ advanced disease has a poor prognosis. It is difficult to diagnose ovarian cancer at an early stage because early disease is typically asymptomatic, early symptoms are non-specific and there is currently no accepted method for population screening.

The benefit of population screening programs for asymptomatic women is yet to be determined. Several large international randomised controlled trials are investigating the potential of population screening to improve early detection of ovarian cancer. The impact of early detection of symptoms of ovarian cancer for effectively treating early disease is not known. Therefore, it is not known whether earlier treatment of symptomatic disease will improve survival of women.

Priority actions:

- 3.1 To monitor the outcomes of trials of population screening for ovarian cancer and to analyse the implications for health programs in Australia (*current initiative: National Cancer Control Initiative*)
- 3.2 To analyse the opportunities for improving survival for women with ovarian cancer by earlier treatment of symptoms by:
 - Reviewing research about symptoms associated with ovarian cancer
 - Studying the occurrence of possible symptoms in Australian women diagnosed with ovarian cancer

- 3.3** Based on 3.2, to develop an evidence-based guide to appropriate strategies for the investigation of symptoms which may be indicative of ovarian cancer for general practitioners, gastroenterologists, urologists, colorectal and general surgeons, medical oncologists and gynaecologists
- 3.4** Based on 3.3, to disseminate and encourage the adoption of the guide about the investigation of symptoms associated with ovarian cancer
- 3.5** Based on 3.2, to develop and disseminate evidence-based information for women about symptoms associated with ovarian cancer

OBJECTIVE 4

To promote optimal management of all women diagnosed with ovarian cancer

The five-year relative survival of women with ovarian cancer after diagnosis is about 42%.³ Adverse prognostic factors for ovarian cancer include older patient age, later stage of disease, higher tumour grade, presence of ascites and residual disease.

Most Australian women with ovarian cancer are treated with surgery and/or chemotherapy. There is some evidence that women with ovarian cancer who are treated by a gynaecological oncologist have improved survival rates.¹¹

Research conducted in Australia and overseas indicates that outcomes are improved for women with cancer who are informed about their treatment options.⁹ Evidence about new treatments for ovarian cancer is emerging from clinical trials and women should be encouraged to participate in available trials.

Priority actions:

- 4.1 To develop, implement and evaluate strategies to encourage referral of women with ovarian cancer to multidisciplinary clinics
- 4.2 To complete and disseminate the *Clinical practice guidelines for the management of epithelial ovarian cancer (current initiative: Australian Cancer Network)*
- 4.3 To develop and conduct strategies to encourage the adoption of guideline recommendations which are not current care

- 4.4 To develop and disseminate a consumer version of the clinical practice guidelines
- 4.5 To provide women with ovarian cancer and their clinicians with information about available clinical trials (*current initiative: ANZGOG*)

OBJECTIVE 5

To strengthen the provision of psychosocial, physical and practical support to all women diagnosed with ovarian cancer and their families.

The diagnosis of ovarian cancer has a major impact on women and their families. Of women diagnosed with ovarian cancer, a high proportion has advanced disease.⁴ Therefore, providing adequate support for women to improve their quality of life is an important component of patient care.

Adequate support and information can improve cancer patients' well being, quality of life and satisfaction with care.⁹ Good communication skills, information provision and continuity of care have also been found to improve quality of life for cancer patients.⁹

Recommendations about the provision of psychosocial support for cancer patients are included in the *Psychosocial clinical practice guidelines for cancers*. Evidence specifically about the supportive care for women with ovarian cancer, however, is limited. Currently, there is limited access to supportive care services in Australian gynaecological oncology units.

Priority actions:

- 5.1 To investigate the supportive care needs of women with ovarian cancer and the needs of their families
- 5.2 To provide adequate information about all aspects of treatment and support to women with ovarian cancer and their families
- 5.3 To conduct communication skills training for health professionals providing care to women with ovarian cancer
- 5.4 To promote to clinicians the evidence about supportive care for cancer patients

OBJECTIVE 6

To develop a national monitoring system for ovarian cancer control in Australia.

Regular and timely monitoring of ovarian cancer control will enable the targeting of new programs and the evaluation of the effectiveness of current programs. Such a monitoring system should be comprehensive including data about incidence, mortality, diagnosis, treatment and supportive care needs of women with ovarian cancer.

There are some data about incidence and mortality available as summarised in the recent report, *Ovarian cancer in Australia*. However, comparisons of data are limited because data are not collected consistently between states. Two studies have examined treatment patterns for Australian women diagnosed with ovarian cancer however, neither is yet published.

Priority actions:

- 6.1** To identify and collate nationally available data about all aspects of ovarian cancer control in Australia
- 6.2** To develop a strategy to standardise existing data collections and to provide a nationally consistent approach
- 6.3** To develop a comprehensive monitoring plan for ovarian cancer which includes strategies for population-based treatment audit, investigation of diagnostic issues, patient satisfaction and quality of care for women
- 6.4** To undertake audits of treatment, diagnosis, and supportive care for women with ovarian cancer, based on the national monitoring plan

OBJECTIVE 7

To provide all women, health professionals, policy makers and the community with access to current, accurate and appropriate information about all aspects of ovarian cancer.

Women, health professionals, policy makers and the community should have access to accurate, appropriate and timely information about relevant aspects of ovarian cancer control.

Evidence from other cancers suggests that there is value in establishing a clearinghouse, providing a central information resource for many audiences.¹⁰ The clearinghouse service might include media programs, a website, and an information bulletin. A particular priority will be reaching generalist and non-gynaecological specialist clinicians. The clearinghouse should be integrated to avoid duplication of information services provided by other organisations, such as OvCa Australia and the Cancer Council Australia.

Priority actions:

- 7.1 To provide a clearinghouse for evidence-based information about ovarian cancer including the development of a national media program, website and regular information bulletin
- 7.2 To conduct programs for health professionals about early detection and treatment of ovarian cancer
- 7.3 To ensure that cancer information services provide accurate and detailed information about ovarian cancer

OBJECTIVE 8

To encourage all organisations concerned with ovarian cancer control to work collaboratively to maintain the impetus to improve ovarian cancer outcomes.

There are many groups working towards improving ovarian cancer control in Australia. Collaborations between these organisations are vital to improving outcomes for women and to maximise the use of resources by avoiding duplication and by introducing varied expertise.

Priority actions:

- 8.1 To work in partnership with other organisations to raise the profile and public awareness of ovarian cancer on the national agenda
- 8.2 To foster a national network of ovarian cancer researchers to encourage collaborative research
- 8.3 To hold national ovarian cancer conferences for all key stakeholders to foster collaboration, share information, review progress, avoid duplication and identify priorities in ovarian cancer

References

1. Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR). *Cancer in Australia 1998*. Canberra: Australian Institute of Health and Welfare, 2001.
2. Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR). *Cancer in Australia 1997: incidence and mortality data for 1997 and selected data for 1998 and 1999*. Canberra: Australian Institute of Health and Welfare, 2000.
3. Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR). *Cancer survival in Australia. Part 1: National summary statistics*. Canberra: Australian Institute of Health and Welfare, 2001.
4. Kristensen, GB. & Trope, C. Epithelial ovarian carcinoma. *The Lancet* 1997; 349:113-7.
5. Mathers, C, Penm, R., Sanson-Fisher, R., Carter, R. & Campbell, E. *Health System costs of cancer in Australia 1993-94*. Canberra: Australian Institute of Health and Welfare and National Cancer Control Initiative, 1998.
6. National Breast Cancer Centre. *Report of the ovarian cancer workshop. Improving outcomes for Australian women with ovarian cancer*. National Cancer Control Initiative, Commonwealth Department of Health and Aged Care, OvCa Australia & the National Breast Cancer Centre, 2001.
7. Mant JW and Vessey MP. Ovarian and endometrial cancers. *Cancer Surveys*. 1994; 19:287-307.

8. Kasprzak L, Foulkes WD, Shelling AN. Hereditary ovarian carcinoma. *BMJ*. 1999, 318:786-9.
9. National Breast Cancer Centre. *Psychosocial clinical practice guidelines for cancers: a guide for those involved with treating and supporting adults with cancer*. (In press)
10. Pillar C, Pelly J, Redman S. A national breast cancer clearinghouse. *Cancer Forum*. 1997; 21: 166-70.
11. Carney ME, Lancaster JM, Ford C, Tsodikov A and Wiggins CL. A population-based study of patterns of care for ovarian cancer: who is seen by a gynaecologic oncologist and who is not? *Gynecologic Oncology*. 2002; 84: 36-42.

APPENDIX A

Priority Action Areas

Workshop – Improving Outcomes for Women with Ovarian Cancer

Four priority action areas were proposed as arising from the Workshop – Improving Outcomes for Women with Ovarian cancer, a collaborative initiative of the National Cancer Control Initiative, the Commonwealth Department of Health and Aged Care, OvCa Australia, and the National Breast Cancer Centre held in September 2001. These covered the areas of Prevention, Early detection, diagnosis and referral, Treatment and Patient Support.

Prevention

Priority Action recommendations:

- Programs should be developed to alert women to evidence about risk factors for ovarian cancer
- Evidence about risk factors for ovarian cancer should be disseminated to clinicians with emphasis on familial risk and genetic links with breast cancer
- Referral by clinicians of ‘high-risk’ women to genetic counselling clinics should be encouraged
- Further research is required to investigate the interactions between genetic and environmental risk factors

Early detection, diagnosis and referral

Priority Action recommendations:

- Professional education programs and public awareness campaigns should be conducted to raise awareness about the early symptoms of ovarian cancer
- Appropriate and timely patient referral by general practitioners and specialists should be promoted through professional education initiatives
- The use of adequate pre-operative assessment should be promoted to encourage a 'triple test' approach

Treatment

Priority Actions recommendations:

- A multidisciplinary team approach for the management of women with ovarian cancer should be promoted. The role of palliative care should be considered as integral to the team
- Strategies should be developed to promote establishment of links between health services to ensure that geographical isolation is not a barrier to quality care. For example, a national service directory could be developed to assist referral between facilities
- Strategies should be developed to disseminate and implement evidence-based clinical practice guidelines to raising clinician awareness of best practice recommendations and to assist with practice improvement

Patient Support

Priority Action Recommendations:

- Evidence-based consumer information for women and families should be developed and made available to women at the time of diagnosis
- Strategies should be implemented to improve access to psychosocial support services at appropriate times, irrespective of patient location
- Strategies should be developed to promote the clinical practice guideline recommendations about the importance of quality of life issues and informing women about treatment side effects and long term effects

APPENDIX B

Interim Ovarian Cancer Steering Group

Dr David Ingram

Director

Mount Hospital Medical Centre

Dr Ian Hammond

Gynaecological Cancer Service of WA

King Edward Memorial Hospital

Professor John Hopper (Chair)

Genetic Epidemiologist

Department of General Practice & Public Health

University of Melbourne

Dr Margaret Davy

Gynaecological Oncologist

Department of Gynaecological Oncology

Royal Adelaide Hospital

Professor Henry Burger

Board Member

Ovarian Cancer Research Foundation (VIC)

Professor Mark Elwood

Director

National Cancer Control Initiative

Professor Alan Coates

Chief Executive Officer

The Cancer Council Australia

Professor Michael Friedlander
Medical Oncologist
Prince of Wales Hospital
Department of Medical Oncology

Professor Alex Crandon
Department of Gynaecological Cancer
The University of Queensland

Professor Adele Green
Deputy Director
Queensland Institute of Medical Research

Ms Tracy Curro
Talking Heads Productions

Dr Amanda McBride
General Practitioner

Professor Neville Hacker
Director
Royal Hospital for Women

Mr Robert Rome
Gynaecological Oncologist

Dr Gerry Wain
Program Director
NSW Cervical Screening Program

Dr Rosemary Knight
Director
Health Priorities Management

Dr Jane Turner
Psychiatrist
Department of Psychiatry
University of Queensland, Mental Health Centre

Mr Simon Lee
Director
OvCa Australia

Dr Chris Milross
Radiation Oncologist
Prince of Wales Hospital

Professor Michael Quinn
Gynaecological Oncologist
Royal Women's Hospital

APPENDIX C

Key Stakeholders

Submissions were sought from key stakeholders regarding the list of priorities prepared at the Interim Steering Group meeting in November 2001

Dr Frances Boyle

Chair

Medical Oncology Group of Australia Inc

Ms Laurann Yen

Acting Chief Executive

ACT Community Care

Dr Virginia Billson

Senior Consultant Pathologist

Mercy Hospital for Women

Ms Karen Livingstone

Director of Awareness

OvCa Australia

Dr Chris Dalrymple

Sydney Gynaecological Oncology

Group (RPA Campus)

Dr Penny Webb

Population and Clinical Sciences Division

Queensland Institute of Medical Research

Professor Robert JS Thomas

Director of Surgical Oncology

Peter MacCallum Cancer Institute

Associate Professor Jonathan Carter
Head
Sydney Gynaecologic Oncology Group

Dr David Allen
Clinical Director
Gynaecology & Surgical Services
Mercy Hospital for Women

Dr Greg Gard
Staff Specialist
Department of Gynaecological Oncology
Royal North Shore Hospital

Mr Damian Davidson
Assistant Manager
Cancer Screening & Control Services
Tasmanian Department of Health &
Human Services

Professor Paul Harnett
Director
Department of Medical Oncology & Palliative Care
Westmead Hospital

Professor Bruce Barraclough
Director
Cancer Services Northern Sydney Health

Professor David Robertson
Monash Medical Centre

Ms Sally Anderson
Deputy Director
Cancer Information & Support Service
Anti-Cancer Council of Victoria

Dr Chris Brown
Chair
Prevention and Early Detection Committee
QLD Cancer Fund

Dr Jenny Thomson
Acting Director
Health Services
Australian Medical Association

Dr Colin Bull ANZGOG
Department of Radiation Oncology
Westmead Hospital

Ms Ellen Kerrins
Manager
Cancer Prevention Unit and Resource Centre
Anti-Cancer Foundation South Australia

Dr Cleola Anderiesz
Project Officer
National Cancer Control Initiative

Ms Denise Hynes
Director of Advocacy
OvCa Australia

Dr Andrew Penman
Chief Executive Officer
The Cancer Council of NSW

Dr S E Baron-Hay
Kolling Institute of Medical Research
Royal North Shore Hospital, Sydney

Dr Felix Chan
Director of Gynaecological Oncology
South Western Sydney Area Health Service (SWSAHS)

Ms Jennifer Muller
Manager
Women's Cancer Screening Services
Public Health Services QLD

Dr David Goldstein
Medical Oncologist
Prince of Wales Hospital

Dr Heather Buchan
Chief Executive Officer
National Institute of Clinical Studies

Dr Kelly-Anne Phillips
Medical Oncology
Peter MacCallum Cancer Institute

Dr Simon Wein
Consultant Physician
Peter MacCallum Cancer Institute

Dr Kathy Tucker
Clinical Geneticist
Hereditary Cancer Clinic
Prince of Wales Hospital

Professor David Healy
Chair
Department of Obstetrics and Gynaecology
Monash Institute of Reproduction and Development

Dr Amanda Goldrick
Staff Specialist
Department of Medical Oncology & Palliative Care
Liverpool Health Service

Dr Lawrie Wright
Executive Officer
Clinical Oncological Society of Australia Inc.

Dr Melissa Robbie
Anatomical Pathology
St Vincent's Pathology

Dr Tony Bonaventura
Senior Staff Specialist
Department of Medical Oncology
Mater Misericordiae Hospital

Professor Bruce Ward
Department of Gynaecological Cancer
University of Queensland

Dr Debra Graves
Chief Executive Officer
The Royal College of Pathologists Australasia

Dr Isabella Smith
Medical Adviser
Centre for Research and Clinical Policy
NSW Health Department

Dr John Carnie
Director
Disease Control and Research
Department of Human Services Victoria

Dr Eleanor Long
Chief Executive Officer
The Royal Australian & New Zealand College of
Obstetricians and Gynaecologists

Professor Robert Burton
Anti-Cancer Council of Victoria

Professor Ian Jacobs
Director
Gynaecological Cancer Research Unit
St Bartholomew's Hospital London

Ms Susan Killion
Executive Director
Health Strategy and Acute Services ACT Health and Community Care

Dr Roger Allison
Director
Royal Brisbane Hospital and Royal Women's Hospital
Health Service Districts

Dr Craig Underhill
Border Medical Oncology
Murray Valley Private Hospital
Wodonga Victoria

Ms Julia Fallon-Ferguson
Co-ordinator
Women's Cancer
Cancer Foundation of Western Australia

Professor David Bowtell
Director
Research
Peter MacCallum Cancer Institute Victoria