

## GLOSSARY

Abdominal	The front portion of the body between the chest and the hips.
Abdominal palpation	A part of physical diagnosis where the hand applies light pressure to the abdomen to determine the condition of the parts beneath the surface.
Adjuvant therapy	A treatment that assists or aids another. The term is used to describe the use of chemotherapy or hormone treatment with or after primary surgery, the aim being to eradicate hidden cancer cells which were not removed at the operation.
Adenocarcinoma	Cancer derived from glandular tissue or in which cells form recognisable glandular structures.
Adnexa	Accessory organs - Fallopian tubes and ovaries.
Adnexal mass - uterine	A growth on an accessory organ such as fallopian tube or ovary.
Aetiology	Cause or causality.
Age-standardised rate	A procedure for adjusting rates eg death rates, designed to minimise the effects of differences in age composition when comparing rates for different populations.
Alcian blue	A dye used to mark tissue to distinguish it from other samples taken during an operation.
Alpha interferon	A glycoprotein used in the treatment of cancer. One of its effects is to inhibit cell growth.
Alternative therapies	A term used to loosely describe any type of therapy outside the orthodox circle of surgery, radiation or chemotherapy. Alternative therapies include things such as diet therapy, vitamins and herbs. ( <i>See also Complementary therapies</i> )
Anastomosis	A surgical connection made between two normally distinct features, for example where repairs are necessary to the bowel following surgery.
Anovulatory	No release of egg from the ovary.
Anxiety	A diffuse highly unpleasant, often vague feeling of apprehension, accompanied by bodily sensations such as pounding heart or sweating. There is an associated anticipation of future misfortune or danger, external or internal.
Apoptosis	Process of cell death.

APRT	Abdomino-pelvic radiation therapy.
Ascites	Abnormal build up of fluid within the peritoneal cavity.
Atypia	Not regular or not conforming to type.
Autosome/autosomal	The chromosomes in the body not concerned with the determination of gender.
Basal pneumonitis	Low level inflammation of lung tissue. A side effect of radiation therapy.
Benign	Not malignant.
Bi-manual pelvic examination	An examination of the pelvis where the doctor feels the organs using fingers inserted into the vagina and/or the rectum.
Body mass index (BMI)	Ratio of weight in kilograms to height in metres <sup>2</sup> . Used as an estimate of total body fat.
Borderline ovarian tumours	A group of epithelial tumours that are not as aggressive as other forms of ovarian cancer. Also referred to as low malignant potential tumours.
Bowel obstruction	A blockage of the bowel which may be the result of surgery or the growth of a tumour.
Brachytherapy	An implant of radioactive materials placed directly near the tumour.
Broad ligament (of uterus)	A band of tissues that connects bones or supports viscera. A double layer of peritoneum.
Brenner tumours	A rare type of epithelial ovarian cancer.
Budding	Asexual reproduction in which a portion of the cell body is thrust out and then becomes separated, forming a new individual.
CA125	A protein or tumour marker which can be detected in blood serum. Elevated levels may also be associated with other malignancies or benign conditions. It is most often raised in serous and less frequently in mucinous cancer and is found in over 80% of non-mucinous epithelial ovarian cancers.
Cancericidal	Destructive to cancer cells.
Cancer registry	A centre in each state and territory where details of cancers are collected to monitor trends.
Carcinoma	Malignant growth; cancer.
Carcinomatosis	The condition of widespread dissemination of cancer throughout the body.

Carboplatin	An anti-neoplastic agent which works by impairing the cancer cells' DNA function.
Case control study	A study that starts with the identification of people with the disease of interest and uses a suitable group without the disease for comparison to assess possible factors involved in the development of the disease. Such studies are often called retrospective as they look back from the outcome to its causes.
Cellular stratification	A pattern of cells where they are arranged in layers.
Chemo-responsiveness	The measure of how a tumour reacts when an anti-tumour drug is administered.
Chemotherapy	The use of drugs or a combination of drugs to kill cancer cells or prevent or slow their growth.
Cisplatin	Chemotherapy agent that works to prevent cancer cells dividing and multiplying.
Clear cell carcinoma	A form of cancer where the cytoplasm of the cell is clear.
Clinical practice guidelines	The bringing together by a central authority of the best available evidence to support recommendations for the prevention, diagnosis and treatment of cancer.
Complementary therapies	A term used to refer to therapies, such as meditation and relaxation therapy, that can work alongside conventional therapy.
Contralateral ovary	The ovary on the opposite side to that containing the tumour.
Counselling	Refers generically to a form of supportive care delivered by all health professionals. There are differing levels of sophistication depending on the training and experiences of the practitioner involved.
Curettage	Removal of growths or other material from wall of a cavity or other surface using a spoon-shaped instrument called a curet.
Cyclophosphamide	An agent used during chemotherapy to kill cancer cells.
Cystadenoma	A cystoma (a cystic tumour) blended with adenoma.
Cystectomy	Removal of an ovary.
Cystitis	Inflammation of the urinary bladder.
Cytokeratins	Any of a group of proteins found in keratin filaments.
Cytology	The study of the origin, structure, function and pathology of cells.

Cytological scraping	(See also diaphragmatic scrapings) Tissue from sites in the body to be tested for the presence of cancer cells.
Cytoreductive surgery	Surgery to remove as much of the tumour as possible to allow for the best possible outcome and to facilitate the effect of chemotherapy.
De novo	Arising as a separate entity, (as new).
Depression	A pervasive or sustained lowering of mood or the loss of interest in nearly all activities. When used clinically, it is a cluster of symptoms or a syndrome, whose other features may include: changes in appetite or weight, sleep or psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating or making decisions; or recurrent thoughts of death or suicide ideation, plans or attempts.
Desmoplastic	Characterised by or causing the formation or development of fibrous tissue.
Diaphragmatic scrapings	Tissue collected from the diaphragm to be tested for the presence of cancer cells.
Docetaxel	Agent used in chemotherapy which inhibits cell division.
Doppler ultrasound	A technique that uses ultrasonic waves to identify abnormal blood flow patterns which may indicate the presence of a tumour.
Doxorubicin/liposomal doxorubicin	Agent used in chemotherapy.
Dysplasia	An abnormality in development.
Efficacy	The ability of a drug or intervention to produce the desired beneficial effect under ideal conditions.
Endocervix	The mucous membrane lining the canal of the cervix (neck of the womb); the region where the cervix opens into the uterine cavity.
Endometriosis	A condition where endometrial-like tissue is found in various locations within the pelvic cavity and elsewhere
Endometrioid	Resembling the endometrium.
Endometrium	The mucous membrane lining the uterus.
Epidemiology	The study of the distribution and determinants of health-related states or events in specified populations and the application of this study to the control of health problems.

Epithelial ovarian cancer	Cancer of the ovary arising in the epithelium (the 'skin' or outer cells) covering the ovary.
Epithelial tufting	Small clumps or clusters forming in the epithelium.
Epithelium	The cellular covering ('skin') of internal and external surfaces of the body consisting of cells joined by small amounts of cementing substances. It is classified according to the number of layers deep and the shape of the superficial cells.
Fat stains	Dyes used to demonstrate fat in tissue being examined under the microscope.
FIGO	Federation Internationale de Gynecologie et d'Obstetrique.
First line therapy	The first administration of therapy such as chemotherapy following surgical removal of the tumour.
Fistulisation	The surgical creation of a fistula; an abnormal tubelike passage within body tissue, usually between two internal organs or leading from an internal organ to the body surface.
Foci	The centre of a process.
Frozen section	A specimen of tissue that has been quick frozen, cut and stained immediately for rapid diagnosis of malignant tissue.
Gastroparesis	Partial or complete paralysis affecting the stomach.
Gemcitabine	An anti-neoplastic agent, given intravenously, which acts by inhibiting DNA and RNA synthesis in cancer cells.
Gene	One of the biologic units of heredity which are situated in specific locations on particular chromosomes in the body. Genes make up the DNA molecules that control cell reproduction and function.
Genesis	(see also histogenesis, pathogenesis, tumourgenesis) The start or origin of a process. Used to denote the production or development of an object or state eg tumorigenesis - the beginning of the development of a tumour.
Genome	A complete set of hereditary factors in the chromosomes.
Germline mutations	Changes in a particular sequence of cells that can be passed on to offspring.
GOG	Gynecologic Oncology Group (USA).
Grade	A score for the degree of cancer growth.

Gynaecological oncologist	A specialist in Obstetrics and Gynaecology awarded the Fellowship of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (FRANZCOG), who has completed a formal three year training program in gynaecological cancer care and has passed the examination for the Certificate of Gynaecological Oncology.
H&E sections	Use of a stain (Hematoxylin-eosin) for routine examination of tissue under a microscope. Cell nuclei are stained deep blue and the surrounds (cytoplasm) pink.
Hepatic enzyme elevation	Increase in the proteins in the liver which acts as catalysts for chemical reactions.
Hilum	Depression or pit at the part of an organ where the vessels and nerves enter.
Histogenesis	The differentiation of cells into specialised tissues forming various organs.
Histology	The study of the minute structure, composition and function of tissues.
HNPCC	Hereditary non-polyposis colorectal cancer. There are fewer polyps than in familial adenomatous polyposis and they tend to occur in the proximal colon.
Homologous	Corresponding in structure, position and origin.
Hypercoagulation	Excessive formation of clots in the blood.
Hyperthyroidism	Excessive activity of the thyroid gland producing symptoms such as weight loss, palpitations and weakness.
Hysterectomy	Surgical removal of the uterus (womb).
ICD	International Classification of Disease.
ICON	International Collaborative of Ovarian Neoplasm Trial.
Ileus	Failure of the appropriate forward movement of bowel contents.
Implants	Material grafted on to a new site or part of the body.
Inanition	Effect of prolonged malnutrition.
Incidence	The number of new cases of illness or disease during a given period in a specified population.
Inclusion cysts	A cyst formed by inclusion of a covering (skin) or lining (gut) in tissue along a line where the body fuses during development.

Infusion	Introduction of a fluid as a saline solution into the blood by gravity flow.
Inguinal	Relating to the groin.
Inhibin	A tumour marker.
Interval debulking	Surgery performed during the first-line chemotherapy but before the completion of the primary treatment.
Intraperitoneal (IP) chemotherapy	Chemotherapy administered through a catheter inserted into the peritoneal cavity
Intravenous (IV) chemotherapy	Administration of a chemotherapy using the veins.
Invasive	Infiltrating the surrounding tissues. A characteristic of malignant tumours.
K-ras	An oncogene mutation.
Laparoscopy	Examination by means of a laparoscope.
Laparotomy	Surgery where an incision is made through the abdominal wall to expose abdominal contents.
Luteinization	The process that takes place in the cells that have matured and discharged eggs.
Lymph nodes	Small, bean-shaped structures (found in the neck, armpit and groin) that filter lymph to prevent harmful agents entering the blood stream. May also be referred to as lymph glands.
Lymphadenectomy	Removal of one or more of the lymph nodes.
Macroscopic	Able to be seen with the naked eye.
Malignant/malignancy	Cancerous.
Malodorous	Having an unpleasant odour or smell.
Menarche	The start of monthly periods.
Menopause	The cessation of monthly periods. This may occur naturally or as a result of surgery or other treatment.
Mesentery	A fold of membrane attaching various organs to the body wall, especially the small intestine to the dorsal wall.
Meta-analysis	A statistical method used to combine the results of different studies on the same topic. Used to pool results from a number of small randomised controlled trials to provide an aggregate that will allow for demonstration of statistically significant results.

Microinvasion	Microscopic extension of malignant cells into adjacent tissue.
Miliary	Lesions resembling millet seeds.
Mitosis	The process of cell division where new cells are formed. Used by the body to replace dead cells.
Morbidity	Term used to report on illness. Can also be used to show persons who were ill, the period of illness and the duration of the illness.
Mortality	Death rate due to a particular cause or disease.
Mortality Hazard Ratio	The ratio of the mortality (hazard) in the treatment or control groups.
Mucinous	Secreting mucous.
Mucositis	Inflammation of the mucous membrane.
Müllerian duct	Paired embryonic ducts that develop into the vagina, uterus and uterine tubes in the female.
Multifocal disease field change	Neoplastic change occurring independently and simultaneously at many sites, in response to the same or related genetic alterations. It may occur as multiple discrete foci (multifocal disease) or as an apparently diffuse process (field effect or field change).
Multidisciplinary care	Multidisciplinary care is the co-ordinated approach using a collaborative group of health professionals and a range of treatment modalities. The team as a whole is responsible for the diagnosis, continuing management and palliative care of the woman with ovarian cancer.
Multidisciplinary team	A group of clinicians and health professionals, from a number of disciplines, working together to manage the care of a patient. The members of the team may include: a gynaecological oncologist, gynaecological pathologist, medical oncologist with special experience in ovarian cancer, radiation oncologist with special experience in ovarian cancer, radiologist with a special interest, general practitioners, specialist nurses, physiotherapists, pharmacists, psychologists, social workers, genetic counsellors, geneticists, and palliative care specialists.
Multi-step adenoma-carcinoma sequence	That sequence of genetic aberrations which predisposes or leads to sufficient genetic instability to cause a full malignant transformation of the affected cells. Conventionally, these steps include firstly a benign neoplastic lesion (ie adenoma) and secondly a malignant neoplastic lesion (i.e. carcinoma).

Mutation	A permanent and transmissible change in genetic material.
Myelosuppression	Suppression of bone marrow activity resulting in a decrease in the number of platelets, red cells and white cells.
Myometrial	The muscular structure of the uterus.
Non-polyposis	Without the formation of numerous polyps.
Nuclear atypia	Irregular or uncommon features in a nucleus.
Nuclei	Plural of nucleus. The body in a cell containing a number of its characteristics.
Nulligravid	Never having given birth.
Omentum	A protective layer of fatty tissue which covers the abdominal organs.
Oncogenes	A gene found in the chromosomes of tumour cells activated in the change of normal cells into cancer cells.
Oophorectomy	Surgical removal of the ovaries. May be bilateral (both ovaries) or unilateral (one ovary).
Open Field Technique	Whole abdominal radiation therapy given to the entire coelomic cavity using a single large portal extending from the domes of the diaphragm to the pelvic floor.
Optimal cytoreduction	Surgery where the residual disease is 2 cm or less.
Oral alkylating agent therapy	An anti-cancer or cytotoxic agent eg a platinum compound. An alkylating agent is one which substitutes an alkyl group for an active hydrogen in an organic compound.
Ovarian capsule	Covering (skin) of ovary.
Ovary	Part of the female reproductive system containing eggs (ova).
Ovulation	Release of egg from the ovary each month.
Paclitaxel	An anti-neoplastic agent, given intravenously, which acts by promoting and stabilising the polymerisation of microtubules.
Palliative care	The active total care of patients whose disease is not responsive to curative treatment. It encompasses the provision of co-ordinated medical, nursing and allied services to help relieve physical symptoms and to provide psychological, emotional and spiritual support.
Papillary	Small, nipple-shaped projections.
Paracentesis	The surgical puncture of a body cavity to collect fluid.

Parenchymal	The essential functioning elements of an organ.
Parity	The condition of a woman who has given birth.
Pathology block	A section outside the site of the tumour taken to test for invasion of cancer cells.
Pathogenesis	The development of a disease, specifically the cellular events, reactions and other pathologic mechanisms that occur.
Pelvis	The lower portion of the trunk forming a basin bounded by the hip bones, sacrum and tail bone.
Periodic acid Schiff (PAS)	Stain colouring sugars red – violet in tissues.
Peritoneal cancer	A variant of ovarian cancer which is found in the peritoneal surfaces.
Peritoneal implants	Growth or insertion of tissue into the peritoneum.
Peritoneal-venous shunt	A device whose purpose is to remove excess fluid (ascites) from the peritoneal cavity and return it to the venous system.
Peritoneal washings	Cells obtained by irrigating the abdominal cavity with saline.
Peritoneum	The serous membrane lining the walls of the abdominal and pelvic cavities.
Phase I, II, III trial	The different stages of a clinical trial. Phase I is designed to evaluate the relationship between dose and toxicity. In Phase II new treatments are screened for their anti-tumour effect, to see which are worthy of further evaluation and in Phase III patients are randomly allocated to receive the new treatment or the best available standard treatment.
Plantar-palmar erythrodyaesthesia	Condition caused by chemotherapy where the soles of the feet and palms of the hands are reddened and sensitive to touch.
Platinum analogue	An element with a similar structure to that of platinum but differing in some respects eg its metabolic action.
Platinum-based chemotherapy	Drugs used to treat ovarian cancer based on platinum eg cisplatin.
Platinum refractory	Disease progression whilst receiving platinum therapy.
Platinum resistant	Initial response to therapy with a platinum agent but with relapse occurring within six months of treatment.
Platinum sensitive	Responsiveness to the administration of platinum-based anti-tumour drug with relapse more than six months after treatment.

Pleomorphism	The assumption of various distinct forms by a single organism.
Pleural effusion	The collection of fluid in the lining of the lungs.
Ploidy studies	Identification of the number of genomes (complete set of chromosomes).
Pooled data	Data from a number of studies combined for analysis to look for an effect/result.
Pouch of Douglas	A sac or recess formed by a fold of the peritoneum dipping down between the rectum and uterus.
Precursor lesion	The forerunner of cancer.
Progression free interval/survival	Interval between the end of first line therapy and relapse.
Prognosis	A forecast as to the probable outcome of a disease and the prospect of recovery based on the nature of the case.
Proliferating	Growth by reproduction of similar cells.
Prophylactic	Something used to prevent disease.
Proportional hazards regression analysis	A mathematical model used to predict risk based on the effect on one variable of a number of independent variables.
Prospective trial/study	A study where subsets of a defined population are identified in relation to a factor/exposure hypothesised to influence the occurrence of a disease or some other outcome. The method used is to observe the population over a sufficient period of time to generate reliable incidence or mortality rates.
Proteomic	Protein patterns.
Psammoma bodies	Containing sand-like or calcareous matter.
Pseudomyxoma peritonei	An uncommon condition with both intra-abdominal and ovarian mucinous tumour present. There is a mass of jelly-like mucus in the pelvis and in many cases, in the upper abdomen.
PTEN	Phosphatase and tensin homologue deleted on chromosome 10. A tumour suppressor gene mutated frequently in a variety of human tumours. PTAN regulates cell growth, cell death and proliferation.
Putative	Commonly regarded as or reputed.

Quality of life	A person's view of their situation and well-being. It encompasses symptoms of disease, side effects of treatment, relationships, occupational and social functioning and a subjective evaluation of adjustment to daily life.
Radiation therapy	Use of X-rays/gamma rays to kill cancer cells.
Randomised controlled trial (RCT)	A study or experiment where subjects are allocated at random to receive or not receive the treatment, procedure or intervention. The results for each group are compared. Generally held to be the most scientifically rigorous method of testing an hypothesis.
Resection	Surgical removal of part of all of an organ or tissue.
Relapse	The return of cancer after it has apparently successful treatment.
Relative risk	The risk (of a disease or death) among those exposed to the risk compared to those who are not exposed to the risk.
Relative survival analysis	Statistical procedure for estimating time people survive with a particular disease when considering different treatments and other factors.
Residual disease	Disease not able to be removed as part of the surgical excision of the tumour.
Retroperitoneal lymph nodes	Lymph nodes situated external or posterior to the peritoneum.
Rhabdomyosarcoma	A highly malignant tumour arising in the muscle or embryonal connective tissue.
SAGE Analysis	Serial analysis of gene expression.
Salpingo-oophorectomy	Surgical removal of fallopian tube and ovary.
Salvage	Salvage (therapy) usually a therapeutic step taken late when other approaches have failed.
Screening	Testing of apparently well persons (those with no symptoms of the disease or condition) to determine whether a disease or condition is present or not.
Secondary cytoreduction	A second operation undertaken to further debulk a tumour in women with persistent disease following a complete course of chemotherapy, or after relapse.
Second-look surgery	Surgery performed after initial surgery or treatment to check on spread or recurrence of disease.
Seeding	The inoculation of other organs with tumour cells.

Sensitivity	The proportion of people who test positive for a disease who are found to truly have the disease.
Septation	The appearance of a wall or partition.
Sequelae	A condition following or occurring as a consequence of another condition.
Serous	Thin or watery like serum.
Serous papillary cystadenocarcinoma	An ovarian tumour derived from glandular tissue. It has features of both cystic and papillary tumours and contains both serum and some solid tissue.
SEST	Surface epithelial stromal tumours.
Specificity	The proportion of people who test negative for a disease who truly do not have the disease.
Surveillance	Watching or monitoring of a disease.
Stage/staging/ stage distribution	The classification of a tumour according to its extent.
Stem cell	Any precursor cell; a blood cell progenitor or 'mother' cell, having the capacity for both replication and differentiation.
Stoma	An opening created surgically from an internal organ to the surface of the body. It is kept open to allow for drainage or other purposes.
Stromal	The tissue forming the ground substance, framework or matrix of an organ as opposed to the functioning part.
Suboptimal debulking	Debulking surgery where residual disease is more than 2 cm.
Synchronous tumours	Tumours occurring at the same time.
Synoptic reporting	Use of pre-formatted reporting systems to capture all the information concerning a tumour.
Tamoxifen	A non-steroidal oral anti-oestrogen.
Taxanes	A group of chemical substances with varying degrees of anti-tumour activity, including paclitaxel, docetaxel and related compounds.
thio-TEPA	N, N', N'', triethylenethiophosphoramidate. A cancer chemotherapeutic agent that largely produces base damage to cells.
Thrombosis	Formation of a clot.

Thromboembolism	Obstruction of a blood vessel with thrombotic material carried by the blood from the site of origin to plug another vessel (blood clot).
Topotecan	A substance used in treatment of ovarian cancer that works by affecting the cancer cells' DNA.
Toxicity	The quality of being poisonous.
Transabdominal ultrasound	Use of high frequency sound waves to identify changes in organs through a hand held device passed over the abdomen.
Transudation	Passage of serum or other body fluid through a membrane or tissue surface.
Transitional carcinoma	That subset of epithelial malignancies that resembles carcinomas occurring in the upper urinary tract and derived from the lining transitional cells.
Transvaginal ultrasound	Use of high frequency sound waves to identify changes in organs through a device inserted into the vagina.
Tubal ligation	Tying off the fallopian tubes to prevent conception.
Tumour	Also called neoplasm. A new growth of tissue in which cell multiplication is uncontrolled and progressive. Tumours are classified in a number of ways the simplest being their origin and whether they are malignant or benign.
Tumour/tumourgenesis	The production of tumours.
Tumour marker	A substance found in the body that suggests the presence of a tumour.
Ultrasound	Use of very high frequency sound waves to examine the structures of the body. The sound is reflected back differently by different types of tissue.
WART	Whole Abdominal Radiotherapy.

## ABBREVIATIONS

APRT	Abdomino-pelvic radiotherapy
BRCA1	
BRCA2	Breast cancer /ovarian cancer susceptibility genes
CA125	Cancer Antigen 125 (see Glossary)
CGO	Certificate of Gynaecological Oncology
CT	Computerised Tomography
FRANZCOG	Fellowship Royal Australian and New Zealand College of Obstetricians and Gynaecologists
FS	Frozen section
GOG	Gynecologic Oncology Group
HCV	Hepatitis C virus
HIV	Human Immunodeficiency Virus
HNPPC	Hereditary non polyposis colorectal cancer
ICON	International Collaborative Ovarian Neoplasm Trial
NHS	National Health Service
NIH (USA)	National Institutes of Health, Bethesda, Maryland USA
PTEN	Phosphatase and tensin homologue deleted on chromosome 10 (see Glossary)
RMI	Risk of Malignancy Index
RPCT	Randomised prospective controlled trial
S/C	Subcutaneous
TVUS	Transvaginal ultrasound
WART	Whole Abdominal Radiotherapy

## **APPENDIX I - ADVICE ABOUT FAMILIAL ASPECTS OF OVARIAN CANCER**

(NB: The following risk categories and management guide for ovarian cancer are based on the guide prepared by the National Breast Cancer Centre (NBCC) Genetics Working Group in 2000 and updated 18 September 2003, following a review of research).

## FAMILIAL ASPECTS OF OVARIAN CANCER

The following categories apply to women **without** breast or ovarian cancer:

1° relatives = *parents, siblings, children*

2° relatives = *aunts, uncles, nieces, nephews, grandparents*

For most Australian women the risk of developing epithelial ovarian cancer to age 75 is approximately 1 in 100

<b>CATEGORIES OF RISK</b>	<p><b>1. At or at most moderately above average risk</b></p> <p>Covers more than 99% of the female population</p> <ul style="list-style-type: none"> <li>No confirmed family history of epithelial ovarian cancer.</li> <li>One 1° or 2° relative diagnosed with ovarian cancer at any age (provided the family is not of Ashkenazi Jewish ancestry*).</li> <li>Two 1° or 2° relatives diagnosed with ovarian cancer, but on different sides of the family (i.e. one on each side of the family).</li> </ul> <p>Lifetime risk of ovarian cancer: 1 in 100 (for most women in this group) but not more than 1 in 30.</p> <p>Risk is no more than 3 times higher than the population average.</p> <p>* High-risk ovarian and breast gene mutations are more common in people of Ashkenazi Jewish ancestry.</p>	<p><b>2. Potentially high risk</b></p> <p>Covers less than 1% of the female population</p> <ul style="list-style-type: none"> <li>One 1° relative diagnosed with epithelial ovarian cancer in a family of Ashkenazi Jewish ancestry*.</li> <li>Two 1° or 2° relatives on the same side of the family diagnosed with epithelial ovarian cancer, especially if one or more of the following features occurs on the same side of the family:               <ul style="list-style-type: none"> <li>additional relative(s) with breast or ovarian cancer.</li> <li>breast cancer diagnosed before the age of 40.</li> <li>bilateral breast cancer.</li> <li>breast <b>and</b> ovarian cancer in the same woman.</li> <li>breast cancer in a male relative.</li> </ul> </li> <li>Three or more 1° or 2° degree relatives on the same side of the family diagnosed with any cancers associated with hereditary non-polyposis colorectal cancer (HNPCC): colorectal cancer (particularly if diagnosed before the age of 50), endometrial cancer, ovarian cancer, gastric cancer, and cancers involving the renal tract.</li> <li>Member of a family in which the presence of a high-risk ovarian cancer gene mutation has been established.</li> </ul> <p>Lifetime risk of ovarian cancer: From 1 in 30 up to 1 in 3, or possibly higher if shown to have a high-risk mutation.</p> <p>Risk may be more than 3 times higher than the population average.</p> <p>*High-risk ovarian and breast cancer gene mutations are more common in people of Ashkenazi Jewish ancestry.</p>

<p><b>MANAGEMENT</b></p>	<ol style="list-style-type: none"> <li>1. Reassure the woman that her risk is at or at most moderately above the average for the general population and that more than 97% of women in this group will not develop ovarian cancer.</li> <li>2. Advise the woman about current best practice for the early detection of cancers for the population.</li> <li>3. Advise the woman to visit her general practitioner promptly with any health changes.</li> </ol> <p>Screening the general population for epithelial ovarian cancer cannot be justified on the basis of the low prevalence of ovarian cancer and the inadequate sensitivity of currently available tests.</p>	<ol style="list-style-type: none"> <li>1. Advise the woman that she has a potentially high risk of developing ovarian cancer and perhaps other cancers, such as breast cancer, but <b>that the majority of women in this group will not develop ovarian cancer.</b></li> <li>2. If the woman wishes to clarify her genetic risk or that of her family, or wishes to consider risk-reducing surgery, discuss referral to a specialist family cancer clinic for advice, appropriate counselling and management.</li> <li>3. Because early detection may be important, and because bilateral salpingo-oophorectomy has been proven to reduce the risk of ovarian and breast cancer in women with a mutation in BRCA1 or BRCA2, advise the woman to see a gynaecological oncologist to discuss her options.</li> </ol> <p>Should a women choose not to have risk-reducing surgery, an appropriate individualised surveillance program may include:</p> <ul style="list-style-type: none"> <li>• visiting her general practitioner promptly with any health changes.</li> <li>• transvaginal ultrasonography.* (The age at which this commences may depend on the family cancer history and if a high-risk ovarian cancer gene mutation has been identified in the woman or her family).</li> <li>• CA125 measurement*. *(There is no evidence that these tests reduce mortality from ovarian cancer but they may be considered for women who have not undergone risk-reducing salpingo-oophorectomy).</li> <li>• surveillance relevant to other cancers (e.g. attending for clinical breast examination, mammography or other surveillance if the family cancer history is consistent with HNPCC).</li> </ul> <ol style="list-style-type: none"> <li>4. Discuss possible participation in a relevant approved clinical trial.</li> </ol>
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## APPENDIX 2 - WORLD HEALTH ORGANIZATION HISTOLOGICAL CLASSIFICATION OF SURFACE EPITHELIAL- STROMAL TUMORS

Source: Sully RE, Young RH and Clemet P. Atlas of Tumour Pathology: Tumours of the Ovary, Maldeveloped Gonads, Fallopian tube and Broad Ligament. Armed Forces Institute of Pathology. Third Series. 1998; Fascicle 23: 28-31.

### **Serous Tumors**

#### **Benign**

Cystadenoma and papillary cystadenoma  
Surface papilloma  
Adenofibroma and cystadenofibroma

#### **Of Borderline Malignancy (of low malignant potential)**

Cystic tumor and papillary cystic tumor  
Surface papillary tumor  
Adenofibroma and cystadenofibroma

#### **Malignant**

Adenocarcinoma, papillary adenocarcinoma, and papillary cystadenocarcinoma  
Surface papillary adenocarcinoma  
Adenocarcinofibroma and cystadenocarcinofibroma (malignant adenofibroma and cystadenofibroma)

### **Mucinous Tumors, Endocervical-like and Intestinal Types**

#### **Benign**

Cystadenoma  
Adenofibroma and cystadenofibroma

#### **Of Borderline Malignancy (of low malignant potential)**

Cystic tumor  
Adenofibroma and cystadenofibroma

#### **Malignant**

Adenocarcinoma and cystadenocarcinoma  
Adenocarcinofibroma and cystadenocarcinofibroma (malignant adenofibroma and cystadenofibroma)

## **Endometrioid Tumors**

### **Benign**

- Cystadenoma
- Cystadenoma with squamous differentiation
- Adenofibroma and cystadenofibroma
- Adenofibroma and cystadenofibroma with squamous differentiation

### **Of Borderline Malignancy (of low malignant potential)**

- Cystic tumor
- Cystic tumor with squamous differentiation
- Adenofibroma and cystadenofibroma
- Adenofibroma and cystadenofibroma with squamous differentiation

### **Malignant**

- Adenocarcinoma and cystadenocarcinoma
- Adenocarcinoma and cystadenocarcinoma with squamous differentiation
- Adenocarcinofibroma and cystadenocarcinofibroma (malignant adenofibroma and cystadenofibroma)
- Adenocarcinofibroma and cystadenocarcinofibroma with squamous differentiation (malignant adenofibroma and cystadenofibroma with squamous differentiation)

## **Epithelial-Stromal and Stromal**

- Adenosarcoma, homologous and heterologous
- Mesodermal (mullerian) mixed tumor (carcinosarcoma), homologous and heterologous
- Stromal sarcoma

## **Clear Cell Tumors**

### **Benign**

- Cystadenoma
- Adenofibroma and cystadenofibroma

### **Of Borderline Malignancy (of low malignant potential)**

- Cystic tumor
- Adenofibroma and cystadenofibroma

### **Malignant**

- Adenocarcinoma
- Adenocarcinofibroma and cystadenocarcinofibroma (malignant adenofibroma and cystadenofibroma)

## **Transitional Cell Tumors**

- Brenner Tumor
- Brenner Tumor of Borderline Malignancy (proliferating)
- Malignant Brenner Tumor
- Transitional Cell Carcinoma (non-Brenner type)

## **Squamous Cell Tumors**

### **Mixed Epithelial Tumors (specify types)**

- Benign
- Of Borderline Malignancy (of low malignant potential)
- Malignant

## **Undifferentiated Carcinoma**

## APPENDIX 3 - PRINCIPLES OF SCREENING

Although the concept of being able to detect ovarian cancer early and thereby reduce the morbidity and mortality from the disease is a highly attractive one, screening programs also have the potential to consume significant health resources and to cause harm to patients. Wilson and Jungner<sup>1</sup> have developed criteria for screening programs:

Principles of screening	
1	The condition should be an important health problem
2	The natural history of the disease should be well understood
3	There should be a recognisable latent or early asymptomatic stage
4	Treatment at an early stage should be of more benefit than treatment started at a later stage
5	There should be a suitable test or examination
6	The test should be acceptable to the population
7	Facilities should be available for the diagnosis and treatment
8	Screening should be repeated at intervals determined by the natural history of the disease
9	The chance of physical or psychological harm to those screened should be less than the chance of benefit
10	The cost of a screening program should be balanced against the benefit it provides.

## SENSITIVITY AND SPECIFICITY OF A SCREENING TEST

**Sensitivity** - is the proportion of those persons who truly have the disease who are identified as having the disease by the screening test i.e. those who are truly positive who test positive. It is the probability that any given case will be identified by the screening test.

**Specificity** - is the proportion of those persons who truly do not have the disease and are so identified by the screening test eg those who are truly negative who test negative. It is the probability of correctly identifying a non-diseased person with a screening test.

A test that has a high sensitivity may give a false positive result. This may result in unnecessary intervention – surgical or otherwise – to establish the correct diagnosis.

'In terms of screening for ovarian cancer, the sensitivity of the test is particularly important, as delay in diagnosis may reduce survival. The specificity of the test also needs to be high, as a failure to differentiate benign disease from malignant disease will lead to unnecessary surgical intervention'.<sup>3</sup>

Tests may be combined or used in a serial fashion to improve the sensitivity and specificity of screening tests.

## POSITIVE PREDICTIVE VALUE

The positive predictive value is the proportion of test results that are truly positive. The positive predictive value reflects not only the sensitivity and specificity of a test but also the prevalence of the disease in the population which is screened.

## DISADVANTAGES OF SCREENING (AUSTOKER 1994)

- Longer morbidity in cases where prognosis is unaltered
- Overtreatment of questionable abnormalities
- False reassurance for those with false negative results
- Anxiety and sometimes morbidity in those with false positive results
- Unnecessary medical intervention in those with false positive results
- Hazard of screening test
- Resource cost: diversion of scarce resources to screening program

## POTENTIAL FOR HARM

The principal ways in which a screening program can cause harm are:

- the adverse effects of the screening test(s);
- the psychological effects of a false positive test;
- the psychological effects of a diagnosis which is made earlier than otherwise with no effective change in health outcome;
- the adverse effects of on-going investigations in women with a false positive screening test results; and
- any delay in diagnosis due to false negative screening results.

### References:

1. Wilson JM and Jungner JJ. Principles and practice of screening for disease. WHO Public Health Paper 34. Geneva: World Health Organization. 1968
2. J M Last. A Dictionary of Epidemiology. Second edition. Oxford University Press. 1988
3. Pearson VAH. Screening for ovarian cancer: a review. Public Health. 1994; 108: 367-382
4. Austoker J. Screening for ovarian, prostatic, and testicular cancers. British Medical Journal. 1994; 309: 315-320

## APPENDIX 4 - GYNAECOLOGICAL ONCOLOGY TRAINING REQUIREMENTS

Gynaecological Oncology is a subspecialty of obstetrics and gynaecology.

Gynaecological Oncologists are specialists in Obstetrics and Gynaecology. In Australia they are awarded the Fellowship of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (FRANZCOG), having completed a formal three year training program in gynaecological cancer care and have passed the examination for the Certificate of Gynaecological Oncology (CGO).

Gynaecological oncologists are competent in the comprehensive management of women with a genital malignancy. The subspecialist will work in gynaecology with at least 66% of the time in gynaecological oncology. They will submit themselves for recertification every three years, and only those actively practising will continue to be certified.

### PATHWAY TO CERTIFICATION AS A GYNAECOLOGICAL ONCOLOGY SUB SPECIALIST VIA THE ROYAL AUSTRALIAN AND NEW ZEALAND COLLEGE OF OBSTETRICIANS AND GYNAECOLOGISTS (RANZCOG) TRAINING PROGRAM

The Gynaecological Oncology Training Program is of three year's duration and comprises clinical training and assessment requirements as follows.

<p><b>Clinical training program</b></p>	<ul style="list-style-type: none"> <li>• must be prospectively approved</li> <li>• at least one year must be spent in a prospectively approved RANZCOG accredited CGO Subspecialty Training Post in Australia</li> <li>• desirable that part of the program is in a prospectively approved unit outside Australia (does not necessarily apply to trainees who have spent at least 12 months of their pre-CGO training in an overseas centre)</li> <li>• minimum number of procedures must be performed</li> </ul>
<p><b>Training documentation</b></p>	<ul style="list-style-type: none"> <li>• Trainee reports completed by Training Supervisor and submitted to the College for each 6-month period</li> <li>• Clinical summaries to be submitted for each 6-month period</li> <li>• All reports must be submitted within 8 weeks of completing each 6-month period</li> </ul>
<p><b>Original research project and thesis</b></p>	<ul style="list-style-type: none"> <li>• thesis must have been finally approved at least three months prior to the date of the oral examination</li> <li>• original research work of sufficient quality to be accepted in a peer-reviewed journal case reports and review articles not acceptable</li> </ul>

<b>Written examination</b>	<ul style="list-style-type: none"> <li>• applications close on 30 April each year</li> <li>• usually held in early August (at same time as MRANZCOG examination)</li> <li>• eligible only if satisfactory Training Assessment Record for 30 months of prospectively approved training</li> <li>• must be attempted for the first time within 2 years of completion of training</li> <li>• maximum of three consecutive attempts allowed</li> <li>• comprises twelve fifteen-minutes short answer questions</li> </ul>
<b>Oral Examination</b>	<ul style="list-style-type: none"> <li>• only eligible if written examination is passed and thesis has been finally approved at least three months prior to the date of the oral examination</li> <li>• usually held each year within six months of written examination</li> <li>• comprises six fifteen-minute and two twenty five-minute stations (with fifteen-minute break). Five minutes preparation before each station is allowed</li> <li>• Histological sections, laboratory worksheets, photographs, journal critiques may be included.</li> </ul>

All RANZCOG Trainees must be supervised by an appointed Training Supervisor/ Program Director.

## PROGRAM OUTLINE

1. The Trainee must have an understanding of the aetiology, epidemiology, screening and prevention of gynaecological malignancy.
2. Skills must be acquired in a wide range of investigative procedures - including cystoscopy, sigmoidoscopy, thoraco-centesis, paracentesis and the placement and care of permanent central intravenous lines. In addition, knowledge and interpretation of relevant ultrasonic, CT, lymphangiographic and other organ imaging techniques must be developed.
3. The Trainee must acquire a high level of skill in colposcopy and in the management of pre-invasive and micro-invasive lesions of the female genital tract.
4. The Trainee must acquire the necessary knowledge and skill to perform radical operations on reproductive organs, and operations on the intestine, urinary and vascular systems, as required in the management of gynaecological cancer and the complications of treatment. Surgical techniques must also be acquired for the dissection of inguinal, pelvic, paraaortic and supraclavicular lymph nodes and reconstructive procedures required for the restoration of pelvic organ function.
5. A sound knowledge of parenteral nutrition and intensive care management of the perioperative patient is required.

6. The Trainees must develop skills in the management of pain and the care of the terminally ill patient.
7. The Trainee must be well-informed about the methods and techniques of radiation therapy, including intracavity and interstitial brachytherapy, external beam therapy and intraperitoneal radioisotope therapy. The Trainee must be capable of participating in the planning of radiation treatment and must acquire an understanding of the principles of radiobiology and radiation physics. The Trainee must develop skills in the management of the side-effects and complications of radiotherapy.
8. The Trainee must acquire an advanced knowledge of the clinical pharmacology of cancer chemotherapy and the practical use of the various drugs required for treatment. The candidate should develop skills in the management of toxic side-effects.
9. The Trainee must develop competence in the assessment of the effects of treatment, and the long-term management of pre-invasive and invasive gynaecological malignancies.
10. The Trainee must develop a sound knowledge of gross and microscopic pathology relevant to gynaecological oncology. This knowledge must be sufficient for the candidate to interpret reports concerning gynaecological malignant histopathology.
11. The Trainee must develop skills in the planning, conduct and reporting of research in gynaecological oncology. In addition he/she must develop a high level of skill in the interpretation and evaluation of research reports.

## ELEMENTS OF THE TRAINING PROGRAM

The Gynaecological Oncology Training Program will consist of **THREE CLINICAL YEARS**, all of which must be prospectively approved. It will include the following elements:

1. Active participation in the work of an approved gynaecological oncology unit for a minimum of TWO years. Because of difficulties in obtaining specific advanced training posts in 'general surgical units' (see below in Paragraph 3), it will be usual for trainees to spend THREE years in gynaecological oncology units.
2. At least ONE year of training will be in an accredited subspecialty training post in Australia.
3. It is desirable, but not mandatory, that there be participation in the work of a general surgical unit, particularly in the areas of gastrointestinal and urological surgery, for ONE year. The work should be at an advanced level and this should be reflected in a logbook of cases.
4. Sufficient participation in the medical oncology management of patients to provide an appropriate training. A specific attachment to a medical oncology unit is not required, but if obtained, no more than THREE months will be accredited.

5. Participation as member of a team planning radiotherapy and performing radiation treatment. A specific attachment to a radiation oncology unit is not required, but if obtained, no more than THREE months will be accredited.
6. Participation in pathology sessions, e.g. Tumour Board Meetings, as related to gynaecological oncology.
7. Participation in the planning, conduct, and reporting of research in gynaecological oncology.

#### Notes

- A:** A maximum of **3 months each** may be accredited for a specific rotation in medical oncology, radiation oncology, palliative medicine, or a related clinical discipline. No more than **two** such rotations will be accredited, i.e., a maximum of 6 months in total. Such a rotation should be for a minimum period of **3 months. Prospective approval should be sought for such a program.** A log book of cases seen, a weekly program, and a summary of training will need to be provided for this discretionary time to be accredited.
- B:** Specific training in research or for higher degrees not involving **clinical** gynaecological oncology is encouraged but not considered to be part of the training program and no reduction in the duration of the training program will be entertained in this respect.
- C:** Trainees commencing the CGO/DGO training program from 1 January 2000 should gain the following minimum number of surgical procedures over the 3 year training period. Trainees will be advised of these requirements at the time of commencement of training. These minimum numbers will be reviewed regularly in the light of submitted training documentation.

Radical hysterectomy & nodes	40
Pelvic nodes	50
Radical vulvar operations	20
Groin node dissections	20
Para-aortic node biopsies	30
Large bowel resections	20
Small bowel resections	20
Ovarian cancer debulking (advanced)	45

This provides a formalised program which gives as far as possible a standard of training. Equally, the College has initiated and pioneered a continuing accreditation program to ensure maintenance of standards.

#### Key point:

- There is a need to ensure that appropriate protocols for training are developed and maintained by the College, as part of the ongoing reaccreditation process, both of individual surgeons and Units.

# APPENDIX 5 – PRACTICAL GUIDELINES FOR THE MANAGEMENT OF SYMPTOMS IN PATIENTS WITH RECURRENT DISEASE

## GASTROENTEROLOGICAL PROBLEMS

### **Nausea and vomiting**

Causes:

- Obstruction
  - Pseudo obstruction (See Constipation)
  - In small and large bowel by cancer, usually multiple sites
  - Gastroparesis
- Constipation
- Chemotherapy
- Inanition

### **Constipation**

Causes:

- Analgesic use
- Poor diet
- Dehydration
- Lack of exercise

## FLUID ACCUMULATION

### **Pleural**

Pleural effusion is often from transudation and may be managed in a variety of ways:

- Pleural tap - relieves symptoms only. May be necessary to make a diagnosis
- Pleuradhesion - using talc, antibiotic or chemotherapy. May be indicated if this is the only sign of disease, or reaccumulation cannot be controlled by any other means
- Concomitant chemotherapy offers the best chance of controlling effusion, if the disease is chemosensitive

## **Peritoneal (ascites)**

Ascites are often a sign of miliary spread of tumour and may be managed in a variety of ways:

- Paracentesis
- Chemotherapeutic control
- Peritoneo-venous shunt - if there is a high output with low particulate matter, and a reasonable prognosis i.e. 2-3 months.

## **Metastasis to 'difficult' sites**

- Brain  
Often associated with reasonable long term survival if this is the only site. Is usually only seen after successful chemotherapy. It is worth using active or aggressive therapy, including surgery and radiation therapy.
- Vaginal disease  
Usually penetration from intraperitoneal sites, with or without fistulation. The major problem is discharge, which is both malodorous and bloody.

## **Thrombo-embolic phenomena**

Malignancy per se is associated with hypercoagulation.

- overt deep venous thrombosis.

The question is at what stage anticoagulation is used and also what type, as monitoring may be an impediment to good quality of life in someone who is dying.

- Heparin - with full scale Warfarin?
- Clexane without monitoring
- No further treatment.

## **Mental trauma**

Psychosocial issues are particularly relevant to women with ovarian cancer.

- Social isolation
- Anxiety
- Depression
- Coping problems

## **Quality of dying**

Two separate scenarios need attention.

- Remission, relapse and then death.

Here, the chemotherapy gives a breather with a response to therapy, but then comes the relapse. The dilemma is how to manage this, where retreatment often produces a second response, and the traumas associated with the reprieve but ultimate failure down the track.

- Chemoresistant disease where the initial chemotherapy does not produce a response.

Second, and often several, lines of chemotherapy are tried and may produce transient but not continues remissions. Hope needs to be tempered with reality and the preparation for death, even during good quality of life periods

## **Preparation for death**

Each of the above scenarios will require a reasonable preparation for death.

## APPENDIX 6 - GUIDELINE DEVELOPMENT PROCESS

In November 2000, the Australian Cancer Network (ACN) established a multidisciplinary working party to develop clinical practice guidelines for the management of women with epithelial ovarian cancer. With the establishment of the National Ovarian Cancer Program in 2001, the National Breast Cancer Centre (NBCC) worked collaboratively with the Australian Cancer Network to develop, revise and complete the guidelines (*see Appendix 8*) in a manner consistent with that prescribed by the National Health and Medical Research Council (NHMRC), and according to the standards indicated by the Quality of Care in Health Outcomes Committee (QCHOC).

Members of the Working Party were representative of the broad organisations from which they came. Three face-to-face meetings were held in the course of developing the guidelines, with a number of executive meetings to monitor progress.

### PURPOSE AND SCOPE OF THE GUIDELINES

#### **Need for clinical practice guidelines for epithelial ovarian cancer**

There are currently no clinical practice guidelines available for clinicians or health professionals who care for women suspected of having, or who are diagnosed with, epithelial ovarian cancer.

#### **Target audience**

These guidelines were developed to assist clinicians, including gynaecological oncologists, gynaecologists, general surgeons, gastroenterologists, urologists and medical and radiation oncologists and other health professionals, provide appropriate care and management for women with epithelial ovarian cancer. The guidelines may also be of interest to consumers and consumer groups, although it is planned to develop a consumer guide, based on the clinical practice guidelines.

#### **Scope of the guidelines**

The guidelines cover aspects of epithelial ovarian cancer from its aetiology, pathology and risk factors for developing the disease to management of women with ovarian cancer and the psychosocial issues for the woman, her family and the clinicians and health professionals caring for her.

#### **Focus of the guidelines**

The primary focus of the *Clinical practice guidelines for the management of women with epithelial ovarian cancer* is to close the gap on information both for medical providers and women, so that awareness of ovarian cancer is raised and the possibility of earlier diagnosis and optimal treatment is realised.

## **Best available evidence**

Literature searches for evidence to support guideline recommendations were undertaken in PubMed, Medline (1966-2003) and other relevant databases. Search terms used to gather information included; 'ovarian cancer'; 'ovarian neoplasm'; 'ovarian carcinoma'; 'epithelial ovarian cancer'; 'borderline ovarian tumours' and 'tumours of low malignant potential'. Within specific areas, for example surgery, the search terms were expanded to cover 'surgical management'; 'treatment'; 'cytoreduction'; 'secondary cytoreduction'; 'interval cytoreduction' ; 'second look surgery'; and so on. From the available abstracts the studies were assessed for their quality, based on aspects such as study type, sample size and inclusion of significance levels and p values. The bibliographies of the initial relevant papers were also used to provide other relevant articles missed in the original search. Members of the Working Party prepared chapters on their topic, summarising the evidence and submitted them for review. Each chapter was submitted for review by an appropriate member of the Working Party or an external invitee.

## **Dissemination and implementation of clinical practice guidelines for epithelial ovarian cancer**

The National Breast Cancer Centre will coordinate the dissemination and implementation of the guidelines. The guidelines for epithelial ovarian cancer will be relevant to gynaecological oncologists, gynaecologists, general surgeons, gastroenterologists, urologists, medical and radiation oncologists and general practitioners.

Strategies for the dissemination and implementation of the guidelines will be drawn from the experience and expertise of the National Breast Cancer Centre, gained through the involvement in the development of a number of clinical practice guidelines.

## **Approval**

The guidelines were approved by the National Health and Medical Research Council (NHMRC) and will be circulated to relevant stakeholders as a critical step to aid dissemination and implementation.

## **Dissemination**

The guidelines will be made widely available through the Internet on the National Breast Cancer Centre's Ovarian Cancer Program web site and Australian Cancer Network's web site. The guidelines can be formatted to allow for downloading and printing. A direct link to the NHMRC website will be included on the websites of the NBCC and the ACN to facilitate access.

Funding is available to initially disseminate copies to gynaecological oncologists, gynaecological clinics, general surgeons, gastroenterologists, urologists and medical and radiation oncologists. Subject to additional funding, copies of the guidelines will be made available to other relevant clinical groups, allied health organisations, State and Territory authorities, cancer treatment centres, consumer groups, professional college and associations and policy makers.

The availability of the guidelines will be widely advertised through a variety of means. This will include notification to relevant:

- professional groups and associations
- cancer council/societies
- state and Territory health authorities
- consumer groups and organisations
- hospitals and cancer treatment centres
- university medical schools
- public policy makers

The guidelines will be advertised through newsletters published by the NBCC, the ACN, other cancer organisations and professional colleges and promoted through presentations at professional meetings and conferences

## **Consultation and feedback**

These guidelines have undergone an extensive consultation process that included both a public consultation process and additional consultation in which the guidelines were sent to professional colleges and other interested parties, such as relevant expert groups, Cancer Council/societies, consumer groups etc, for review. (*A list of submissions received is provided in Appendix 7*)

## **Consideration of local conditions and resources**

The opportunity to implement some of the recommendations may be limited by the availability of, or access to, resources such as provided by multidisciplinary teams. For some situations the guidelines present both the optimal situation and recommendations for what can be realistically achieved given limited resources.

## **Evaluation**

A strategy for evaluating the guidelines will be drafted at the implementation stage and will include collection of data to determine the impact of the guidelines on the care of women with epithelial ovarian cancer. This may include repetition of studies which investigated care patterns for women prior to the implementation of the guidelines.

## Revision of guidelines

It is anticipated that the *Clinical practice guidelines for the management of women with epithelial ovarian cancer* will be revised in 2009.

## Future research needs

- Centres for education and research in histopathology of rare and variant ovarian tumours. Such centres would have unusual or otherwise difficult or interesting cases referred to them for further diagnosis
- A laboratory centre at which specialised histologic functions such as uncommon immunohistochemistry and DNA analysis can be performed
- A randomised, prospective study to clarify the role of secondary cytoreduction with randomisation between chemotherapy alone and surgery followed by chemotherapy for patients with a disease-free interval of at least 2 years and no evidence of ascites
- Randomised controlled trial to compare the efficacy and toxicity of Whole Abdominal Radiation Therapy (WART) alone versus chemotherapy alone as adjuvant therapy for ovarian cancer
- A randomised study to develop a template for appropriate follow up for women with ovarian cancer

## APPENDIX 7 - RESPONDENTS TO PUBLIC CONSULTATION

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## APPENDIX 8 - AUSTRALIAN CANCER NETWORK MANAGEMENT OF WOMEN WITH EPITHELIAL OVARIAN CANCER WORKING PARTY

The Australian Cancer Network (ACN) Management of Women with Epithelial Ovarian Cancer Working Party was established in 2000 to guide the development of the *Clinical practice guidelines for the management of women with epithelial ovarian cancer*. The Working Party is a multidisciplinary working group comprising representatives from a range of specialities. With the establishment of the National Ovarian Cancer Program in 2001, the National Breast Cancer Centre (NBCC) joined the Working Party.

### TERMS OF REFERENCE

- i. To develop evidence-based guidelines to provide optimal management for malignancies of the ovary.
- ii. To address the magnitude of the problem of ovarian malignancy and optimise management and cost factors to achieve control.
- iii. To promote optimal care of malignancies of the ovary and achieve NHMRC accreditation of the guidelines produced, to provide evidence-based best practice care for malignancies of the ovary.
- iv. To present guidelines in a range of formats, to meet requirements of specialists, general practitioners, associated health professionals and consumers.

### MEMBERSHIP OF THE ACN MANAGEMENT OF WOMEN WITH EPITHELIAL OVARIAN CANCER WORKING PARTY

Dr Margaret Davy AM (Chair)	Gynaecological Oncologist
Dr Kaye Birks	General Practitioner
Dr Colin Bull	Radiation Oncologist
Dr Jennifer Doust	Epidemiologist
Dr David Grimes	Medical Oncologist
Professor Neville Hacker	Gynaecological Oncologist
A/Professor Paul Harnett	Medical Oncologist
A/Professor Judy Kirk	Medical Geneticist
Ms Eugenia Koussidis	Consumer
Ms Letitia Lancaster	Oncology Nurse
A/Professor Andrew Ostor#	Pathologist
A/Professor Michael Quinn	Gynaecological Oncologist
Dr Melissa Robbie	Histopathologist
Dr Alison Venn	Epidemiologist
Emeritus Professor Tom Reeve AC CBE**	Convenor
Ms Jane Francis*	Manager
Dr Karen Luxford*	Program Director

Corresponding members:

Mr Robert Rome

Gynaecological Oncologist

Dr Gerard Wain

Gynaecological Oncologist

\* Ovarian Cancer Program, National Breast Cancer Centre \*\* Senior Medical Advisor, Australian Cancer Network

# Deceased January 2003

## REVIEW PANEL FOR PUBLIC SUBMISSIONS - 29 APRIL 2003

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Honorary Senior Clinical Advisor, National Cancer Control Initiative

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Gynaecological Oncologist. Chair, ACN Working Party

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Gynaecological Oncologist

Professor Peter Russell

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## ACKNOWLEDGMENTS:

The following are also gratefully acknowledged for their contribution to these guidelines:

Dr Mary Brooksbank - Palliative Care

Professor Alan Coates AM - Medical Oncology

Professor Michael Friedlander - Medical Oncology

Professor John Hopper - Medical Genetics

Dr Anne Krickler - Epidemiology

Professor Helen Lapsley - Health Economics

Dr Jennifer Leary - Molecular biology

Professor Norelle Lickiss - Palliative Care

Professor Ian Maddocks - Palliative Care

Professor Lester Peters - Radiation Oncology

Associate Professor Kelly-Anne Phillips - Medical Oncology/Medical Genetics

Associate Professor David Roder AM - for contributing sections on the aims of cancer registries and clinical cancer registry data from South Australia

Staff of the National Cancer Statistics Clearing House, AIHW, particularly Dr Paul Jelfs,

Ms Edith Christensen and Mr Krystian Sadkovsky

Dr Christopher Steer - Medical Oncology

Dr Martin Stockler - Medical Oncology

Professor Martin Tattersall - Medical Oncology

Ms Vicky Thursfield of the Cancer Epidemiology Unit, Anti-Cancer Council of Victoria

Dr Jane Turner - Psychiatry

## APPENDIX 9 - RESOURCES AND CONTACTS FOR PATIENTS AND HEALTH PROFESSIONALS

### RESOURCES

The following guides and reports are available from the National Breast Cancer Centre (NBCC).

- Advice about familial aspects of breast cancer and ovarian cancer: a guide for health professionals (card). (*Currently being reviewed*)
- Ovarian Cancer in Australian Women
- Priority actions for ovarian cancer control: a framework for a national approach
- Report of the Ovarian Cancer Workshop. Improving outcomes for Australian women with ovarian cancer

### RESOURCES FOR HEALTH PROFESSIONALS

#### **Communication skills training**

Information on Communication Skills Training for clinicians may be obtained from:

National Communication Skills Training Strategy

National Breast Cancer Centre

Ph: (02) 9036 3030

Fax: (02) 9036 3077

Email: [director@nbcc.org.au](mailto:director@nbcc.org.au)

Website: [www.nbcc.org.au/bestpractice/communication](http://www.nbcc.org.au/bestpractice/communication)

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Fax: (02) 9926 7730

Email: [pam.mclean@med.usyd.edu.au](mailto:pam.mclean@med.usyd.edu.au)

Website: [www.mcleancentre.org](http://www.mcleancentre.org)

## **Resources for health professionals, women and their families**

Detailed information about available resources for specific cancers can be obtained from the Cancer Helpline or State and Territory cancer organisations (see contact details listed later in this section).

The Internet also has a considerable amount of information about cancer. A good place to start searching the Internet is through the Home Page of reputable cancer organisations/associations or support networks. A list of recommended Internet sites is also available in Appendix 13.

## **CONTACTS**

To learn more about cancer and the services and support available to a woman and her family, the following contacts may be helpful.

### **Nationally**

#### ***Cancer Helpline***

The Cancer Helpline provides general information as well as information on local resources. This service can be accessed from anywhere in Australia for the cost of a local call, connecting to local cancer organisations.

Ph: 13 11 20

#### ***Ovarian Cancer Program - National Breast Cancer Centre (NBCC)***

In September 2001, the Commonwealth Government announced the establishment of The Ovarian Cancer Program, to be implemented by the National Breast Cancer Centre. The Program aims to improve outcomes for women with ovarian cancer by providing the most accurate, evidence-based information available to both women and health professionals.

Contact details are:

Locked Bag 16

Camperdown NSW 1450

Ph: (02) 9036 3030

Fax: (02) 9036 3077

Email: [director@nbcc.org.au](mailto:director@nbcc.org.au)

Website: [www.ovariancancerprogram.org.au](http://www.ovariancancerprogram.org.au)

#### ***The National Cancer Control Initiative (NCCI)***

The NCCI is a partnership between the Cancer Council Australia and the Australian Government Department of Health and Ageing. It provides advice on all issues related to cancer control and manages a range of cancer related projects. The Initiative works closely with other bodies and takes account of the National Health Priorities of the Commonwealth Government. The Initiative can also provide information and access to

Australian Cancer Organisations and other Australian Health Links including Australian Government and State and Territory Health Departments.

Contact details are:

1 Rathdowne St

Carlton VIC 3053

Ph: (03) 9635 5108

Fax: (03) 9635 5320

Email: [enquiries@ncci.org.au](mailto:enquiries@ncci.org.au)

Internet: [www.ncci.org.au](http://www.ncci.org.au)

### ***The Cancer Council Australia***

Australia's national non-government cancer control organisation. Its members are the eight State and Territory cancer organisations. They work together to undertake and fund cancer research, prevent and control cancer and provide information and support for people affected by cancer.

Contact details are:

Level 5 92-94 Parramatta Road Camperdown NSW 2050

Ph: (02) 9036 3100

Fax: (02) 9036 3101

Email: [info@cancer.org.au](mailto:info@cancer.org.au)

Website: [www.cancer.org.au](http://www.cancer.org.au)

### ***Australian Cancer Network (ACN)***

Established by The Cancer Council Australia and the Clinical Oncological Society of Australia to improve cancer management and promote collaboration between and with professional bodies across Australia. It extends the outreach of the Cancer Council Australia to a large number of professional colleges and societies. The ACN has developed and disseminated evidence-based clinical practice guidelines for several areas of cancer management.

Contact details are:

Mail: GPO Box 4708

Sydney NSW 2001

Ph: (02) 9036 3120

Fax: (02) 9036 3121

Email: [acn@cancer.org.au](mailto:acn@cancer.org.au)

### ***National Health and Medical Research Council (NHMRC)***

Government body that brings together and draws upon the resources of all components of the Australian health system. It funds health and medical research, provides ethical guidance on health and medical research issues, and provides health advice. It publishes guidelines, information papers and pamphlets on a range of health issues, drawing on the best expert advice and ensuring that the published advice is both current and relevant for the Australian community.

Contact details are:

GPO Box 9848

Canberra ACT 2601

Ph: 02 6289 9148

Fax: 02 6289 9197

Website: [www.nhmrc.gov.au](http://www.nhmrc.gov.au)

### ***Australian Council of Stoma Associations (ACSA)***

The ACSA represents all stoma associations throughout Australia. It provides liaison with the Australian government and appliance suppliers and coordinates the Stoma Appliance Scheme. The ACSA also coordinates support services for ostomates throughout Australia and publishes a national journal. The ACSA can provide patients who have undergone stomal surgery access to local associations and support groups, and information and advice about locally available resources.

Contact details are:

Website: [www.australianstoma.org.au](http://www.australianstoma.org.au)

### ***Palliative Care Australia***

The national peak body for palliative care in Australia with member groups in each of the States and Territories. Their goal is to work toward the relief of pain and suffering of dying people and the provision of the care they, and their families, need. Contact details are listed below. State and Territory contact details can be obtained from the national body.

Contact details are:

PO Box 24

Deakin West ACT 2600

Ph: (02) 6232 4433

Fax: (02) 6232 4434

Email: [pcainc@pallcare.org.au](mailto:pcainc@pallcare.org.au)

## STATE AND TERRITORY CANCER ORGANISATIONS AND ASSOCIATED NUMBERS

State and Territory Cancer Councils provide information and educational resources on all types of cancers. Some have lending libraries. Many cancer organisations have also developed their own publications about cancer and treatments. To find out about cancer support groups and other local services, State or Territory cancer organisations and the Cancer Helpline should be contacted.

### *The Cancer Council ACT*

159 Maribyrnong Avenue

Kaleen ACT 2617

Ph: (02) 6262 2222

Fax: (02) 6262 2223

**Email:** [reception@actcancer.org](mailto:reception@actcancer.org)

**Website:** [www.cancer.org.au/act/](http://www.cancer.org.au/act/)

### *The Cancer Council New South Wales*

153 Dowling St

Woolloomooloo NSW 2011

Ph: (02) 9334 1900

Fax: (02) 9358 1452

**Email:** [feedback@nswcc.org.au](mailto:feedback@nswcc.org.au)

**Website:** [www.cancercouncil.com.au](http://www.cancercouncil.com.au)

### *The Cancer Council Northern Territory*

Casi House

Unit 1-3

25 Vanderlin Dr

Casuarina NT 0810

Ph: (08) 8927 4888

Fax : (08) 8927 4990

**Email:** [admin@cancernt.org.au](mailto:admin@cancernt.org.au)

**Website:** [www.cancercouncilnt.com.au](http://www.cancercouncilnt.com.au)

### *The Cancer Council Tasmania*

140 Bathurst St

Hobart TAS 7000

Ph: (03) 6233 2030

(03) 6233 2088

Fax: (03) 6233 2123

**Email:** [infotas@cancer.org.au](mailto:infotas@cancer.org.au)

**Website:** [www.cancer.org.au/tas](http://www.cancer.org.au/tas)

*The Cancer Council Victoria*

1 Rathdowne St  
Carlton South VIC 3053  
Ph: (03) 9635 5000  
Fax: (03) 9635 5270  
Email: [enquiries@cancervic.org.au](mailto:enquiries@cancervic.org.au)  
Website: [www.accv.org.au](http://www.accv.org.au)

*The Cancer Council South Australia*

202 Greenhill Rd  
Eastwood SA 5063  
Ph: (08) 8291 4111  
Fax: (08) 8291 4122  
Email: [tcc@cancersa.org.au](mailto:tcc@cancersa.org.au)  
Website: [www.cancersa.org.au](http://www.cancersa.org.au)

*The Cancer Council Western Australia*

46 Ventnor Ave  
West Perth WA 6005  
Ph: (08) 9212 4333  
Fax: (08) 9212 4334  
Email: [inquiries@cancerwa.asn.au](mailto:inquiries@cancerwa.asn.au)  
Website: [www.cancerwa.asn.au](http://www.cancerwa.asn.au)

*Queensland Cancer Fund*

553 Gregory Terrace  
Fortitude Valley QLD 4006  
Ph: (07) 3258 2200  
Fax: (07) 3257 1306  
Email: [qldcf@qldcancer.com.au](mailto:qldcf@qldcancer.com.au)  
Website: [www.qldcancer.com.au](http://www.qldcancer.com.au)

## ACTION AND SUPPORT GROUPS

### ***OvCa Australia (National Ovarian Cancer Network)***

A 'not-for-profit' organisation that aims to increase awareness of ovarian cancer, to promote the need for effective early detection and to provide support to women and families. OvCa has implemented a 'Buddy Support' program through which women with ovarian cancer can access one-to-one support from a volunteer who is themselves either a patient with ovarian cancer or a supporter or carer.

Contact details are:  
PO Box 2365  
Fitzroy VIC 3065  
Ph: 1300 660 334  
Email: [info@ovca.org](mailto:info@ovca.org)  
Website: [www.ovca.org](http://www.ovca.org)

## **Other**

For information about local action and/or support groups not listed above, or teleconference support, patients can contact local State and Territory organisations or the Cancer Helpline on 13 11 20.

## SUPPORT GROUPS FOR SPECIFIC DIFFICULTIES

### ***Lymphoedema Associations & Support Groups***

These groups provide information on lymphoedema, local services and resources and support. Some states and territories also have regional and special interest support groups. Contact numbers are available from the state or territory lymphoedema organisations.

#### *The Lymphoedema Association of Australia*

Dr Judith Casley-Smith (Chair)

94 Cambridge Terrace

Malvern SA 5061

Ph: (08) 8271 2198

Fax: (08) 8271 8776

Email: [casley@internode.on.net](mailto:casley@internode.on.net)

Website: [www.lymphoedema.org.au](http://www.lymphoedema.org.au)

#### *Lymphoedema Support Group, ACT*

Jenny Moore

Peter Sack

19 Bardsley Place

5 Hobbs Street

Holt ACT 2615

O'Connor ACT 2602

Ph: (02) 6254 4753

Ph: (02) 6249 8672

#### *NT Lymphoedema Support Group*

PO Box 42719

Casuarina NT 0811

Ph: (08) 8927 4888

Fax: (08) 8927 4990

#### *Lymphoedema Support Group, NSW*

204/5-9 Everton St

Pymble NSW 2073

Ph: (02) 9402 5625

Fax: (02) 9402 5774

#### *Lymphoedema Association of QLD*

Ms Jean Lowe (Secretary)

PO Box 68

Brackenridge QLD 4017

Ph: (07) 3833 4376

Fax: (07) 3269 7305

Branches at Brisbane, Bundaberg, Mackay & Torquay

*Lymphoedema Support Group of SA*

Ms Maureen Bartel (Chairperson)

26 Sandford St

Kensington Gardens SA 5068

Ph: (08) 8431 4190

**Email:** [bartel.maureen@saugov.sa.gov.au](mailto:bartel.maureen@saugov.sa.gov.au)

*Tasmania Lymphoedema Support Group*

Ms Jill Wood

42 Stanley St

Bellerive Hobart TAS 7018

Ph: (03) 6244 4632

*Lymphoedema Association of Victoria Inc*

Ms Mary D'Elia

PO Box 2412

North Ringwood VIC 3134

Ph: 1300 852 850

**Email:** [info@lav.org.au](mailto:info@lav.org.au)

**Website:** [www.lav.org.au](http://www.lav.org.au)

*Lymphoedema Association of Western Australia*

Joan Shepherd (Secretary)

PO Box 2037

Claremont North WA 6010

Ph: 0500 576 000

## CONTINENCE SUPPORT GROUPS

### ***Continence Foundation of Australia***

The Continence Foundation of Australia exists to serve the interests of incontinent people throughout Australia by improving access to and availability of services, providing information and advice and promoting education, support and research.

The Foundation can be contacted at:

AMA House 293 Royal Parade

Parkville VIC 3052

Ph: (03) 9347 2522

Fax: (03) 9347 2533

**Website:** [www.contfound.org.au](http://www.contfound.org.au)

## ***National Continence Helpline***

The National Continence Helpline is a joint project of the Commonwealth Government and the Continence Foundation of Australia. It provides free, professional and confidential advice about any continence issue to people with incontinence, their families and carers. The Helpline also provides supplementary information for medical and allied health professionals

Ph: 1800 330 066

In addition to the National Office the Foundation also has State and Territory branches as follows:

### *CFA Victoria*

C/- St George Health Service

283 Cotham Rd

Kew VIC 3101

Ph: (03) 9816 8266

Fax: (03) 9816 8366

**Email:** [cfavic@continencevictoria.org](mailto:cfavic@continencevictoria.org)

**Website:** [www.continencevictoria.org](http://www.continencevictoria.org)

### *CFA ACT*

Community Care, Continence Clinic

PO Box 825

Canberra City ACT 2601

Ph: (02) 6205 3308

Fax: (02) 6206 1162

### *CFA Western Australia*

C/- Hollywood Private Hospital

GPO Box 591

Claremont WA 6910

Ph: (08) 9386 9777

Fax: (08) 9389 8001

**Email:** [continencewa@optusnet.com.au](mailto:continencewa@optusnet.com.au)

### *CFA South Australia*

Contact National Office

Ph: (03) 9347 2522

Fax: (03) 9347 2533

### *CFA New South Wales*

C/0 Cumberland Hospital

PO Box 2522

North Parramatta NSW 1750

Ph: (02) 9890 4165

Fax: (02) 9840 4163

**Email:** [contfoundnsw@ozemail.com](mailto:contfoundnsw@ozemail.com)

*CFA Tasmania*

Contact National Office

Ph: (03) 9347 2522

Fax: (03) 9347 2533

*CFA Northern Territory*

Specialist Health Service

Territory Health Services

Ph: (08) 8922 7283

Fax: (08) 8922 7399

Email: [gail.mcbean@nt.gov.au](mailto:gail.mcbean@nt.gov.au)

*CFA Queensland*

Contact National Office

Ph: (07) 9347 2522

Fax: (03) 9347 2533

*Alice Springs (CFA NT)*

C/- Adolescent & Adult Health Services,

Community Health Services Centre

PO Box 721

Alice Springs NT 0871

Email: [sandra.clyne@nt.gov.au](mailto:sandra.clyne@nt.gov.au)

## **Look Good...Feel Better**

A community service for women undergoing cancer treatment, sponsored by the Cosmetic, Toiletry and Fragrance Association of Australia Inc., dedicated to teaching women beauty techniques to help restore their appearance and self-image during chemotherapy and radiotherapy. Workshops are held every 6-8 weeks at selected cancer treatment centres. For further information, contact:

National Helpline: 1800 650 960

## **Services for lesbian women**

Peer-based counselling about sexual health/health-related issues is available over the telephone through the Gay and Lesbian Community Services of Australia.

NSW, QLD, VIC and WA	1800 184 527.
SA	1800 182 233.
Tasmania	1800 633 900
NT	1800 184 527 (call will be re-directed to SA contact)

## APPENDIX 10 - FINANCIAL ASSISTANCE FOR TRAVEL AND ACCOMMODATION

Patients travelling to the city for treatment may be eligible for a government scheme to provide financial assistance for travel and accommodation expenses. However, many patients are unaware of their eligibility for this support. This scheme has a different name in each State and Territory:

ACT	Interstate Patient Travel Assistance Scheme (IPTAS)
NSW	Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS)
NT	Patient Assistance Travel Scheme (PATS)
QLD	Patient Travel Subsidy Scheme (PTSC)
SA	Patient Assistance Transport Scheme (PATS)
TAS	Patient Travel Assistance Program (PTAP)
VIC	Victorian Patient Transport Assistance Scheme (VPTAS)
WA	Patient Assisted Travel Scheme (PATS)

Patients should be advised that they may need to claim in advance in some states. In some states, support is available for family members, and some states also have patient accommodation available through the cancer organisations or hospitals at reduced costs. A list of available resources can be obtained from each State and Territory cancer organisation or local hospital.

## APPENDIX 11 - SERVICES FOR PATIENTS FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS

The Translating and Interpreting Service (TIS) is a national service with offices in each State and Territory. The service offers both telephone and face-to-face interpreting. If an interpreter is needed to attend an appointment, this will need to be booked a few days in advance. TIS is available 24 hours a day, 7 days a week. The TIS can be contacted from anywhere in Australia, for the cost of a local telephone call, on 13 14 50.

Some states and territories also have other interpreter services available in a range of community languages. Some have health interpreters who are specially trained to interpret medical terms and procedures. The service is usually free of charge in public hospitals (some services do charge a fee). In addition to the interpreter services listed below, the patient's GP or local Departments of Social Security may be able to provide information on additional services in their area.

### *National (Australia Wide)*

Translating and Interpreting Service (TIS) 13 14 50 (local call cost, 24 hour).  
To book an on-site interpreter call 1300 655 081

### **ACT**

ACT Health Care Interpreters (02) 6205 3333

### **NSW**

Health Care Interpreter Service

Central & South Eastern Sydney	(02) 9515 3222
Northern Sydney	(02) 9926 7560 (02) 9962 5772 (A/H)
South Western Sydney	(02) 9828 6088 (02) 9616 8111 (A/H)
Western Sydney & Wentworth	(02) 9840 3456 (02) 9840 3456 (A/H)
Hunter	(02) 4924 6285 (02) 4921 3000 (A/H)
Illawarra	(02) 4274 4211
Greater Murray and Southern	1800 247 272
All other country areas	1800 674 994

## **NT**

Northern Territory Interpreter and Translator Service

Darwin 1800 676 254

Alice Springs (08) 8951 5389

Aboriginal Translator services

Darwin (08) 8924 4300

(08) 8924 4223

Alice Springs (08) 8951 5576

(09) 8924 3400

## **QLD**

No other accredited interpreter services. Call TIS: 13 14 50

## **SA**

Interpreting and Translating Centre (ITC), Multicultural and Ethnic Affairs Commission (08) 8226 1990

## **TAS**

AMIGOS Translate (03) 6288 5480

## **VIC**

Central Health Interpreting Service (CHIS) (03) 9370 1222

Victorian Interpreting and Translating service (03) 9280 1955

## **WA**

Multicultural Access Unit - Translation Service (08) 9400 9512

## APPENDIX 12 - MULTICULTURAL CANCER INFORMATION SERVICE

This is a telephone service in Arabic, Cantonese, Mandarin, Greek and Italian for those diagnosed with cancer and their families.

### What does the service provide?

- information about cancer in Arabic, Cantonese, Mandarin, Greek and Italian to those diagnosed with cancer and their families
- a confidential telephone service
- information workers who speak Arabic, Cantonese, Mandarin, Greek and Italian. Each information worker also speaks English
- emotional support for people diagnosed with cancer and their families and friends
- information about referral to other services related to cancer
- information about cancer including investigations and treatment options
- information on attitudes and beliefs related to cancer in people from non-English speaking backgrounds for health care providers and community workers
- feedback to doctors and other health care providers about the person's concerns (at the person's request)
- information for the media about cancer
- information sessions to language specific community groups
- some assistance to bilingual cancer support groups
- bi-lingual brochures on cancer.

### About the Information Workers

The information workers are trained in the clinical, cultural and psychosocial aspects of cancer. They have a background in nursing, social work and counselling. The information workers receive regular debriefing sessions by a psychologist or counsellor.

For further details, contact the Service on (02) 9334 1758.

### Contact details for the Bilingual Information Workers:

These numbers may be called from NSW and anywhere in Australia for the cost of a local call. The days listed are the 'usual' days of operation, but they may vary.

Arabic	Monday, Tuesday & Thursday	1300 301 625
Cantonese and Mandarin	Monday to Friday	1300 300 935
Greek	Tuesday, Thursday & Friday	1300 301 449
Italian	Monday, Thursday & Friday	1300 301 431

## APPENDIX 13 - RECOMMENDED INTERNET SITES

This is not an exhaustive list but gives some indication as to what is available.

### **Australian**

*The Ovarian Cancer Program*

[www.ovariancancerprogram.org.au](http://www.ovariancancerprogram.org.au)

*The Cancer Council Australia*

[www.cancer.org.au](http://www.cancer.org.au)

Australia's national non-government cancer control organisation.

*The Cancer Council Victoria*

[www.accv.org.au](http://www.accv.org.au)

Victoria Cancer Council information and educational resources for all types of cancers.

*The Cancer Council of South Australia*

[www.cancersa.org.au](http://www.cancersa.org.au)

South Australia Cancer Council information and educational resources for all types of cancers.

*The Cancer Council New South Wales*

[www.cancercouncil.com.au](http://www.cancercouncil.com.au)

NSW Cancer Council information and educational resources for all types of cancers.

*HealthInsite*

[www.healthinsite.gov.au](http://www.healthinsite.gov.au)

A wide range of up-to-date and quality assessed information on important health topics including cancer is available on this site.

*OvCa Australia (National Ovarian Cancer Network)*

[www.ovca.org](http://www.ovca.org)

Information on the OvCa Australia website is oriented for patients and others personally affected by ovarian cancer. Information is provided on symptoms, statistics, news and other links.

*OvCare*

<http://128.250.188/ovcare/>

OvCare is a national initiative focusing on ovarian cancer research and education. Website has general information on ovarian cancer, research projects and links to other cancer sites.

*Ovarian Cancer Research Foundation*

[www.ocrf.com.au](http://www.ocrf.com.au)

The Ovarian Cancer Research Foundation (OCRF) has been established to foster research into ovarian cancer. The website provides general information on ovarian cancer, research projects, news and fund raising events.

*Peter MacCallum Cancer Institute*

**[www.petermac.org](http://www.petermac.org)**

Peter MacCallum Cancer Institute is a comprehensive specialist oncology centre providing cancer services in Melbourne and throughout Victoria, Australia. Website includes information about the institute's services and cancer library.

*National Cancer Control Initiative*

**[www.ncci.org.au](http://www.ncci.org.au)**

The NCCI is a partnership between the Cancer Council Australia and the Australian Government Department of Health and Ageing. It provides advice on all issues related to cancer control as well as manages a range of cancer related projects.

*Australian Society of Gynaecologic Oncologists (ASGO)*

**[www.users.bigpond.com.asgo](http://www.users.bigpond.com.asgo)**

Provides a list of current practising Gynaecological Oncologists and has a list of Gynaecological Oncology Departments.

*Gynaecological Cancer Society*

**[www.gcsau.org](http://www.gcsau.org)**

Information on website is for patients, carers & families, professionals and students. The information is holistic, authoritative and cancer specific, covering the full range of gynaecological cancers.

*Clinical Trials Centre (NHMRC)*

**[www.ctc.usyd.edu.au](http://www.ctc.usyd.edu.au)**

Details of clinical trials and other research conducted in Australia.

## **International**

*National Cancer Institute*

**[www.cancer.gov](http://www.cancer.gov)**

Information developed by the US National Cancer Institute for health professionals, the general public, and cancer researchers from a variety of sources. Also offers links to Cancer Trials.

*University of Pittsburgh Cancer Institute*

**[www.upci.upmc.edu](http://www.upci.upmc.edu)**

A National Cancer Institute-designated Comprehensive Cancer Centre

*American Cancer Society*

**[www.cancer.org](http://www.cancer.org)**

Useful site providing information about cancer including information about the American Cancer Society, its publications, programs and local offices

*CancerBACUP*

**[www.cancerbacup.org.uk](http://www.cancerbacup.org.uk) / [www.cancerbacup.org.uk/ovary](http://www.cancerbacup.org.uk/ovary)**

The UK's leading cancer information service

<http://cancer.med.upenn.edu>

Sponsored by the University of Pennsylvania Cancer Centre. Directed towards physicians, health professionals, social workers, and cancer patients including their family and friends.

*Institute of Cancer Research*

[www.icr.ac.uk](http://www.icr.ac.uk)

Information about the Institute plus information for patients and families.

*International Agency for Research on Cancer*

[www.iarc.fr](http://www.iarc.fr)

Part of the World Health Organisation and responsible for coordinating and conducting research on the causes of human cancer.

*National Comprehensive Cancer Network (NCCN) and American Cancer Society (ACS)  
Cancer Treatment Guidelines for patients*

[www.nccn.org](http://www.nccn.org)

The NCCN and ACS have translated the NCCN Oncology Practice Guidelines into easy-to-understand information that can assist patients and families in making medical decisions. While some guidelines provide information about breast, colon and rectal, lung, and prostate cancer, the others provide information about cancer related physical symptoms such as fatigue, pain, and nausea and vomiting. Access is available by clicking on the 'NCCN/ACN treatment guidelines' link in the above website.

*PubMed*

[www.ncbi.nlm.nih.gov/entrez/query.fcgi](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi)

US National Library of Medicine's search service. Provides access to citations in MEDLINE and other databases.