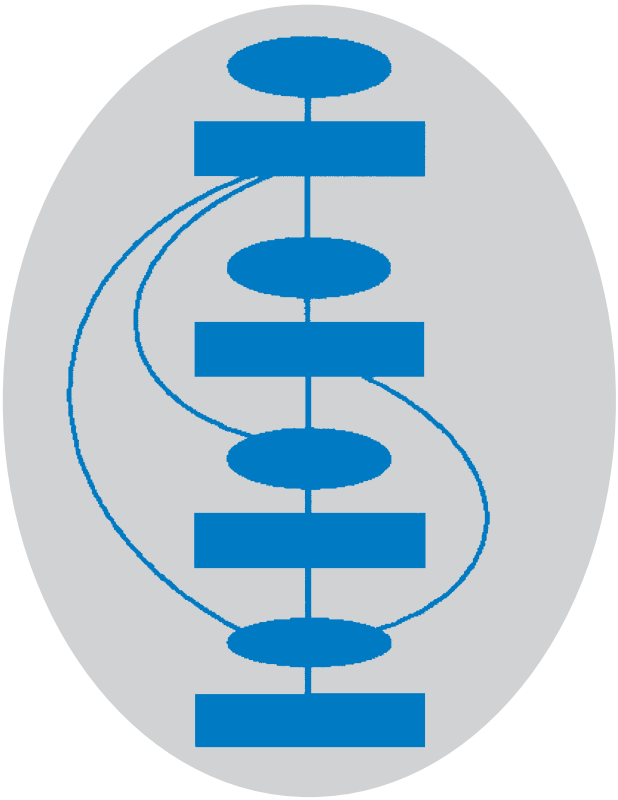
GOOD PRACTICE

Guidance on Commissioning Cancer Services

Improving Outcomes in Gynaecological Cancers

The Manual



NHS Executive

Purpose of this document

This booklet is intended to help Chief Executives of Health Authorities and NHS Trusts review and identify ways to improve services for gynaecological cancers.

GOOD PRACTICE

Examples of and advice on good practice

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Catalogue number	**16149**
Date of issue	**July 1999**

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Contents

The Topic Areas

Appendices

Foreword

This latest report in the National Cancer Guidance series is different from its predecessors (on breast, colorectum, and lung cancer) in three important respects.

- It is service-based rather than disease-based. Thus it covers all the cancers conventionally regarded as part of gynaecology, even though these form a somewhat disparate group of diseases, with very different clinical features and patterns of management.

- It deals with diseases which differ markedly in their survival rates. Women with ovarian cancer have much poorer long-term survival rates than those with cervical or endometrial cancer, who do relatively well.

- It covers cancers which are considerably less frequent than those covered in this guidance series so far. There is one new case of ovarian cancer for every six cases of breast cancer, and only one case each of cervical and endometrial cancer for every nine cases of breast cancer. Taken together all gynaecological cancers occur at less than half the rate for breast cancer.

A district hospital (DGH) serving a quarter of a million population is likely to receive about one new case of ovarian cancer each fortnight and fewer than one new case per fortnight of cervical or endometrial cancer. A general practitioner (GP) will only see a new patient with ovarian cancer every five years or so and a new endometrial or cervical cancer patient about every seven to nine years.

These low volumes put into perspective the challenge of developing workable and reliable operational arrangements for the care of these patients, and prompt difficult questions about the optimum configuration of the relevant services. For example, what level in the health care system is most likely to deliver the best results, and to do so efficiently? Where should the multiprofessional and multidisciplinary focus be for formulating decisions about the management of individual patients? What are the consequences for clinical professionals and for resources of moving workload from one part of the health care system to another?

The recommendations in this report are underpinned by the same basic principles on the organisation of services as in earlier reports. We have looked at published research and at evidence about the performance of current services. We recognise that the most critical aspects of clinical decision-making and service delivery require sufficient caseload to justify bringing together the scarce specialist skills and facilities necessary to permit effective multiprofessional and multidisciplinary care. This needs to be balanced against the provision of care as close to the patient's home as is compatible with high quality, safe and effective treatment. The ultimate test for any proposed service model is the goal set out in Calman-Hine,[1] to consistently achieve the best possible outcomes for patients.

Whilst the recommendations set out in this document actively involve all three Calman-Hine levels, primary care, Cancer Units, and Cancer Centres, the overall balance is undoubtedly more centralist than previously. The service model for gynaecological cancers is built around assessment services at DGH/Cancer Unit level and treatment services at Cancer Centre level (with appropriate specialist teams).

In formulating these recommendations we have opted for the service model most likely to give good outcomes. If this is achieved successfully it is much more likely that women with these cancers will receive optimum investigation, assessment, and treatment. It must never be forgotten that one of the driving forces behind the Calman-Hine policy is that audited cancer care across the UK has in the past been shown to be extremely variable. The goal for commissioners, as well as clinicians, must be to ensure that the means of delivering an optimum service are systematically applied across the country.

As with previous reports we have sought to separate the provision of services for symptomatic patients from the operation of national screening programmes such as that for cervical cancer. During the current decade screening has begun to significantly reduce the numbers of cervical cancer cases, a trend which shows no sign of ceasing. We have recognised the need to ensure that any changes arising from implementing this guidance do not inadvertently create problems for the conduct of the cervical cancer screening programme as it is currently delivered. We believe there is nothing in these recommendations which will adversely affect this important service.

Professor R A Haward
Chairman - National Cancer Guidance Steering Group

References

1. NHS Executive. *A policy framework for commissioning cancer services.* EL(95)51, Department of Health, 1995.

Introduction

This manual is intended to guide commissioning, planning and development of gynaecological cancer services. It follows on from the Calman-Hine Report, *A Policy Framework for Commissioning Cancer Services*[1] and forms part of the Department of Health strategy as set out in Executive Letter EL(96)15, paragraph 8 and Annex C.

The guidance concentrates on those aspects of services which are likely to have significant impact on health outcomes. The recommendations represent a set of priorities in areas most likely to make a difference to patients, not a "shopping list" of all relevant health care activities or everything to be commissioned. Both the resource implications and the anticipated benefits of implementing the recommendations are considered.

This manual is neither a set of mandatory instructions nor is it a detailed set of clinical practice guidelines. Many of the recommendations made here may have already been implemented in some places; the guidance can be used to identify gaps in local provision and to check on the appropriateness of existing services.

It is not anticipated that all the proposals described will be achieved in all areas. Some may be easy to implement, while others will be goals at which to aim. Health authorities and primary care groups will need to identify which of these to prioritise, taking into account the quality and configuration of existing local services and the resources available. It might seem reasonable to prioritise on the basis of the likely impact of change - as far as this may be judged from the evidence - but this too depends on the degree to which the current service differs from that which is recommended.

The topic areas covered vary widely and the evidence suggests that change in some areas will have more impact than in others. The amount and strength of supporting evidence available also varies, partly reflecting the fact that research has tended to focus on some issues more than others. Unanswered questions and areas of uncertainty remain. Some of these are being studied in well designed and co-ordinated clinical trials, in which all commissioners, units and centres should be encouraged to participate, to contribute to improvements in knowledge about the best way to prevent and treat gynaecological cancers. It is anticipated that this guidance will be updated when significant new evidence becomes available.

Local circumstances will necessitate modifications in the way this guidance is implemented. For example, services suitable for sparsely populated areas, where access can be difficult, may be different from those provided in cities. Cultural and ethnic differences may also require differences in provision. Local people and GPs should be involved in discussions about the configuration of local services and the nature of the care to be provided.

How the guidance was produced

The guidance is a result of an extensive, explicit and rigorous multi-stage process developed by the Chief Medical Officer's Cancer Guidance Group, chaired by Professor Haward of Leeds University *(Appendix 1)*. A wide range of individuals from professional, policy and patient groups was involved in generating proposals for recommendations which were then critically appraised in the light of research evidence *(Appendix 2)*. Finally, the material was synthesised and refined, taking account of the resource implications.

The first stage of the production process for gynaecological cancers guidance took place at a two-day event at which a large group of relevant health care professionals, people with personal experience of gynaecological cancers, health care commissioners and academics from around the country, met to put forward structured proposals based on their experience and knowledge of the research literature. These proposals were then sent to referees, including clinicians, academics, representatives of health authorities, the Department of Health, patient organisations, and relevant charities, many of whom made detailed comments and suggestions. Systematic reviews of the research literature were then carried out or commissioned by the NHS Centre for Reviews and Dissemination at the University of York.

This process culminated in the production of two large sources of information, one with a practical or operational focus and the other containing detailed research evidence on effectiveness. The guidance draws on both these sources, with added input from commissioners, patients, and experts in the particular fields who gave advice. It was written by the NHS Centre for Reviews and Dissemination with input from the National Cancer Guidance Editorial Group, and informed by focus groups of commissioners.

A complementary piece of research was commissioned from the School of Health and Related Research at the University of Sheffield. The aim of this project was to examine the potential cost implications of the reconfiguration of services into Cancer Units and Centres recommended in the guidance (see Topic 1, *Specialist Services and Multiprofessional Teams*). This work involved literature searching, interviews with clinicians and managers and analysis of cancer registry, activity data and Healthcare Resource Group reference costs. A more detailed model was produced for ovarian cancer than for the other gynaecological cancer sites, and case studies were used to illustrate the potential impact.

The production of this guidance was funded by the NHS Executive.

The organisation of the guidance material

The guidance material is divided into two documents, in which the topic areas are discussed in the same order for ease of cross-reference. This order is intended to be a logical sequence of issues and does not reflect priorities.

The first document *(The Manual)* is based on all the available sources of information. Each topic area includes five sections which summarise: (A) the recommendations, (B) potential benefits of implementing them, (C) the strength of the supporting evidence, (D) how implementation may be measured, and (E) the resource implications of implementing the recommendations. The only references included in this manual are to guidelines and other sources of information which are not reports of research.

The second document (*The Research Evidence*) is a condensed version of systematic reviews of research which was used to inform the guidance. It includes tables with information about individual studies and is fully referenced. This document includes the final report of the commissioned costing work.

The recommendations are also available as a four page summary designed for GPs and primary care teams.

The Topic Areas

1. Specialist Services and Multiprofessional Teams
2. The Patient's Perspective
3. Ovarian Cancer: Pre-treatment Assessment
4. Ovarian Cancer: Treatment
5. Endometrial Cancer: Diagnosis and Pre-treatment Staging
6. Endometrial Cancer: Treatment
7. Cervical and Vaginal Cancers: Diagnosis and Staging
8. Cervical and Vaginal Cancers: Treatment
9. Vulval Cancer
10. Post-treatment Support and Follow-up
11. Palliative Treatment and Care

The Research Evidence

In order to ensure that the guidance is anchored in the research evidence, the research literature was reviewed and critically appraised. The reliability and quality of evidence which supports the recommendations is graded throughout this document[2]. These grades refer to the nature of the evidence, not the strength of the recommendations. The grades are as follows:

A. Evidence derived from randomised controlled trials or systematic reviews of randomised trials.
B. Evidence from non-randomised controlled trials or observational studies.
C. Professional consensus.

It should be recognised that the quality of research evidence forms a continuum. It is categorised here for convenience but there is overlap between categories. Most of the published research on gynaecological cancers focuses on clinical evaluations of treatment; relatively little direct research has been carried out on the organisation and delivery of services. In addition, for many service delivery issues, randomised controlled trials (categorised here as the highest quality evidence) may not be feasible. Therefore, research designs which might be regarded as of relatively poor quality for evaluating a clinical intervention may be the most reliable available for assessing the effectiveness of service delivery.

References

1. NHS Executive. *A policy framework for commissioning cancer services.* EL(95)51, Department of Health, 1995.
2. Mann T. *Clinical Guidelines: using clinical guidelines to improve patient care within the NHS.* NHS Executive, 1996.

Key Recommendations

- Dedicated diagnostic and assessment services should be established in Cancer Units, to which all women with possible or suspected gynaecological cancers should be referred. This includes women with symptoms and those who present through the cervical screening programme.

- There should be specialist multiprofessional gynaecological oncology teams based in Cancer Centres. These teams should be responsible for the management of all women with ovarian cancer and the majority of women with other gynaecological cancers.

- The specialist gynaecological oncology and palliative care teams in each Cancer Centre and associated Cancer Units should agree clear local policies for the management of women with advanced or progressive disease. These policies should be designed to ensure the co-ordination of high quality care between Cancer Centres, Cancer Units, palliative care, primary care and community services.

- There should be rapid and efficient communication systems for liaison and cross-referral between all levels of service. Audit should take place across the entire service delivery network, including the Cancer Centre and all related Units.

Background

Gynaecological cancers are a diverse group of diseases with different natural histories and responses to treatment. The most common cancers in this group affect the ovaries, cervix or endometrium (lining of the uterus); cancers of the vulva and vagina and other cancers of the uterus (sarcomas) are relatively rare (Table 1).

Table 1. Gynaecological cancers: Incidence and deaths, England and Wales.[1]

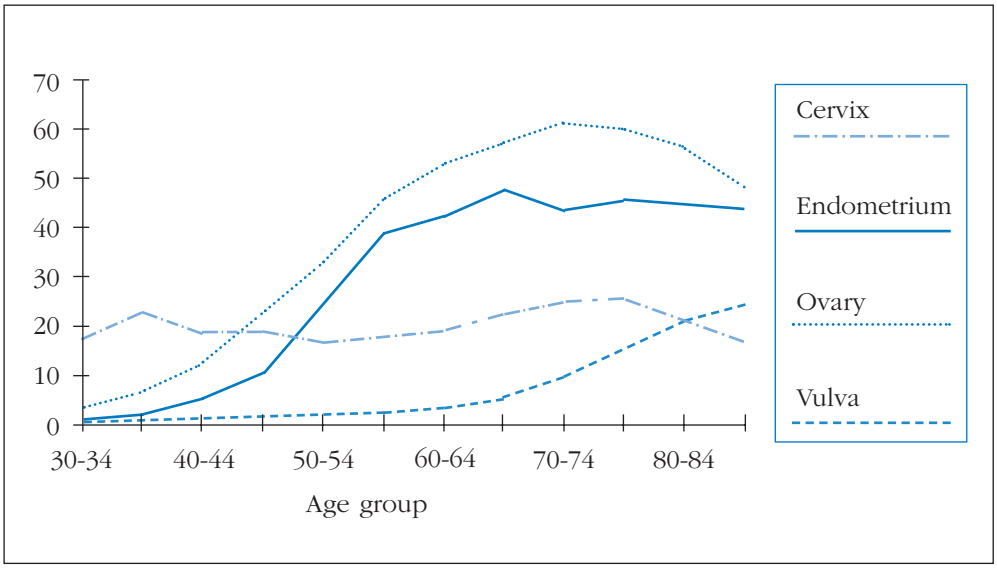
Cancer site	ICD9 code	Number of registrations, 1992	Incidence rate per 100,000 women, 1997[a]	Deaths, 1997	Death rate per 100,000 women, 1997
Ovary	183	5,388	20.3	3,985	15.0
Endometrium	182	3,912	13.8	774	2.9
Cervix	180	3,400	10.4	1,225	4.6
Vagina	184.0	209	0.8[b]	89	0.3
Vulva	184.4	803	3.1[b]	346	1.3

[a] Estimated incidence

[b] Actual incidence, 1992

Gynaecological cancers accounted for approximately 6,400 deaths in England and Wales in 1997, an overall rate of 24 per 100,000 women (just over half the breast cancer death-rate). Ovarian cancer is responsible for more deaths than all the other gynaecological cancers combined, ranking fourth after breast, lung and bowel cancer as one of the leading causes of cancer death in women.[1] While cervical cancers occur with similar frequency in women of all ages over 30, the incidence of cancers of the endometrium and ovary rises with age (Figure 1).

Figure 1. Rates of newly diagnosed cases of gynaecological cancers per 100,000 women, England and Wales, 1992.



Source: Office of National Statistics. [1]

Ovarian cancer

Ovarian cancer includes a heterogeneous group of tumours, some of which are of borderline malignancy. The incidence is higher in older women, better educated women and women from higher social classes. Reduced ovulation, whether due to oral contraceptive use, pregnancy (especially below age 25) or early menopause, is associated with reduced risk.[3] 5-10% of women with ovarian cancer have a family history of the disease; for women under 45 with more than one affected relative, the risk of developing the disease by age 75 is about 14%.[4] Genetic syndromes which lead to marked increases in the risk of ovarian cancer may also be associated with a high risk of breast cancer (BRCA1 and BRCA2 genes) or colon cancer (HNPCC gene).

Diagnosis of ovarian cancer can be difficult. The most common symptoms - persistent abdominal distension, pain, a feeling of pressure in the pelvis - can be caused by a variety of conditions and ovarian cancer may not be suspected. Other symptoms include abnormal vaginal bleeding, bowel symptoms and a pelvic mass. In the majority of cases, the disease has progressed to a late stage by the time it is diagnosed.[5]

Prognosis after diagnosis of ovarian cancer is poorer than for other gynaecological cancers. Figures for England suggest that the 5-year survival rate is only about 26%,[6] but recent data from Yorkshire show 32.4% surviving.[2]

Studies of screening for ovarian cancer have failed to show that it can improve outcomes, but randomised trials are currently in progress to assess its effectiveness.

Surgery is the first-line treatment but chemotherapy, normally involving platinum compounds in combination with other cytotoxic drugs, is also used for women with higher stage ovarian cancer.

Endometrial cancer

The incidence of endometrial cancer is low (under 2 per 100,000) in women under 40 years old but rises rapidly between the ages of 40 and 55, levelling off after the menopause at around 44 per 100,000.[1]

Women who have relatively high levels of oestrogen are at higher risk of endometrial cancer. These include women who are obese (which is associated with increased production of oestrogen by the body); who have used oestrogen replacement therapy unopposed by progestogens or tamoxifen (used to treat breast cancer); and those with polycystic ovary disease.

The main symptom is vaginal bleeding. Since endometrial cancer is most common in post-menopausal women, it is usually diagnosed at an early stage. Surgery (hysterectomy) is often sufficient to treat the disease, but radiotherapy is used when the cancer is more advanced. Recent figures for England show that the age-standardised 5-year survival rate is just over 70%.[2,6]

Cervical cancer

The main risk factor for cervical cancer is infection with the sexually transmitted human papilloma virus.[7] Multiple sex partners, early onset of sexual activity, and smoking are associated with cervical cancer. The disease is twice as common in women from lower social classes (IIIM, IV, V) as it is in social classes I, II and IIIN.

Population screening to identify women with pre-cancerous lesions known as cervical intraepithelial neoplasia (CIN), which may progress to cancer, has been associated with a recent decline in the incidence of cervical cancer. However, screening is not designed to detect adenocarcinoma, which accounts for around 10-15% of invasive cervical cancers.[5,8]

Cervical cancer may cause abnormal vaginal bleeding (particularly after intercourse) and pain. Surgery is used to treat early cervical cancers, but radiotherapy is often necessary when the cancer is more advanced. A 55% 5-year survival rate has been reported for England,[6] but more recent Yorkshire figures show 67% survival.[2]

Vaginal cancer is similar in nature to cervical cancer but much less common.

Vulval cancer

Vulval cancers are rare, particularly amongst younger women. Symptoms may include itching or soreness which fails to respond to topical treatment, a lump, or a persistent ulcer. Surgery is the main method of treatment. The 5-year survival rate for England is 51%[6] (57% in Yorkshire[2]).

Palliative treatment and care

A variety of interventions, ranging from surgery to supportive care, may be necessary to improve quality of life for women going through the late stages of gynaecological cancer. Palliative treatment and care of women with advanced disease accounts for a considerable proportion of the total cost of managing these cancers.

Structure of Services

A range of services and different levels of specialisation are likely to be appropriate to deal with different cancers and stages. Various options and pathways are available, ranging from treatment in local Cancer Units for relatively straightforward interventions, to management by specialist multiprofessional gynaecological cancer teams working in Cancer Centres for more advanced, rarer, or more challenging cancers.

A diagrammatic representation of services required for appropriate referral of women with possible gynaecological cancers is given in Figure 2 below.

References

1. Office for National Statistics. Data provided on request.

2. Northern and Yorkshire Cancer Registry and Information Service. Unpublished data, 1998.

3. Tavani A, Negri E, Francheschi S, *et al.* Risk factors for epithelial ovarian cancer in women under age 45. *European Journal of Cancer* 1993;**29A**:1297-301.

4. Stratton JF, Pharoah P, Smith SK, *et al.* A systematic review and meta-analysis of family history and risk of ovarian cancer. *British Journal of Obstetrics and Gynaecology* 1998;**105**:493-9.

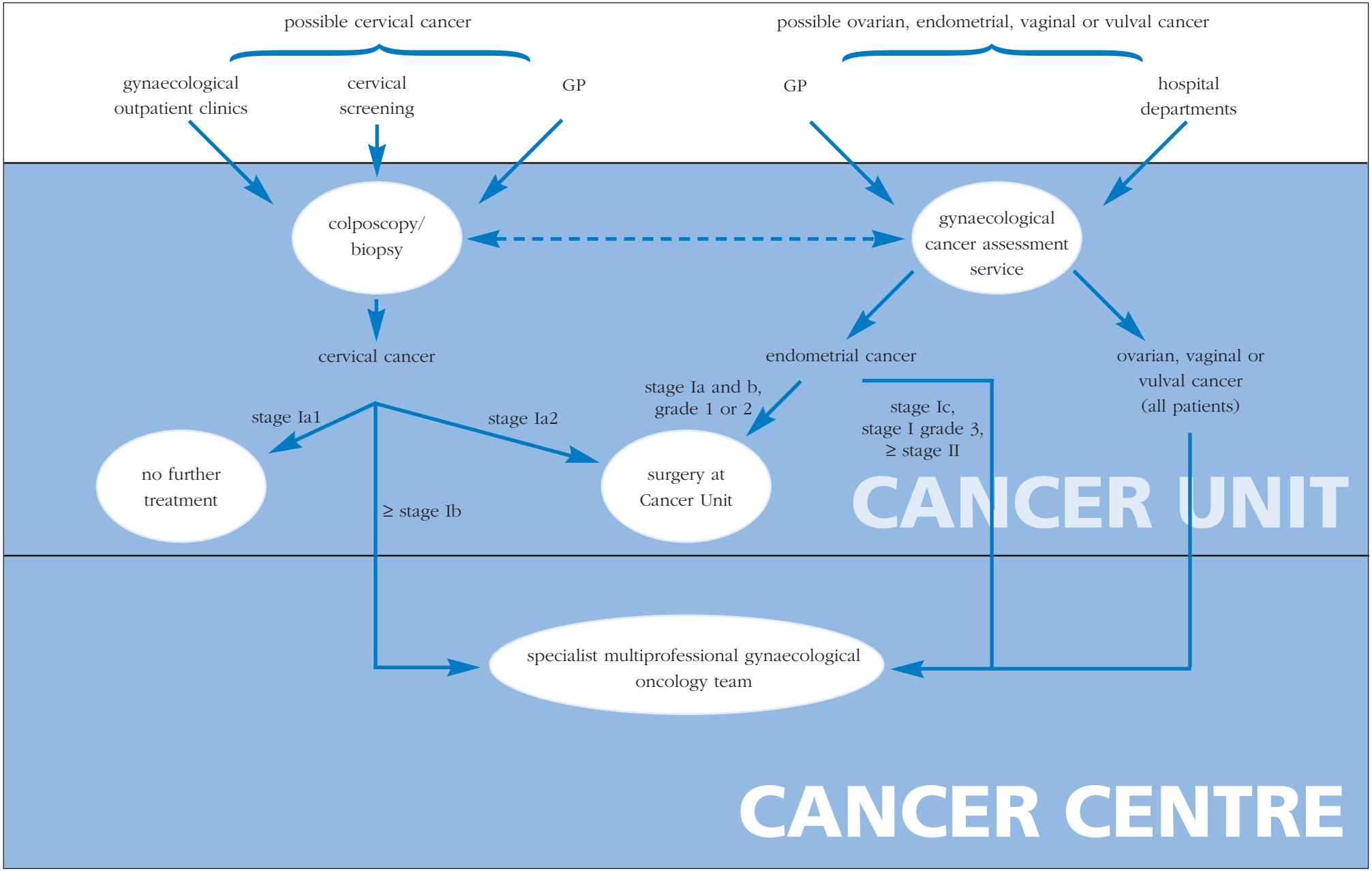
5. FIGO Annual Report Editorial Board. FIGO annual report on the results of treatment in gynaecological cancer. *Journal of Epidemiology and Biostatistics* 1998;**3**.

6. Berrino F, Sant M, Verdecchia A, *et al.*, (eds). *Survival of cancer patients in Europe: the EUROCARE study.* Lyon: International Agency for Research on Cancer, 1995.

7. Bosch FX, Manos MM, Munoz N, *et al.* Prevalence of human papillomavirus in cervical cancer: a world-wide perspective. International biological study on cervical cancer (IBSCC) Study Group. *Journal of the National Cancer Institute* 1995;**87**:796-802.

8. van Wijngaarden WJ, Duncan ID, Hussain KA. Screening for cervical neoplasia in Dundee and Angus: 10 years on. *British Journal of Obstetrics and Gynaecology* 1995;**102**:137-42.

Figure 2: Flow diagram for referral of possible cases of gynaecological cancer



Specialist Services and Multiprofessional Teams

1

A. Recommendations

The optimum management of gynaecological cancers requires co-ordinated teamwork between three levels of service: primary care, Cancer Units and Cancer Centres, as described by Calman and Hine.[1]

The Cancer Unit should provide a local rapid assessment service for all types of gynaecological cancers, and treat superficially invasive cervical disease and early cancers of the endometrium. Specialist support from a Cancer Centre will be required in some cases. Women with all other tumours (ovarian cancers, later stage endometrial cancers, cancers of the cervix, vulva or vagina) should be referred to Cancer Centres following initial assessment at the Cancer Unit, since these tumours are relatively rare or present particular challenges. Documented, mutually agreed criteria for rapid referral and effective channels of communication between primary care, Cancer Units and Cancer Centres are crucial.

The Cancer Unit

Women with symptoms or signs that could be caused by cancer should receive rapid and appropriate assessment at the local level. This should be provided by a designated Cancer Unit which includes a team whose members have a special interest in gynaecological cancer.

Members of the Cancer Unit Team

- A lead gynaecologist who will be responsible for the assessment of patients with possible gynaecological cancer.
- A lead pathologist with a special interest in malignant gynaecological disease, who should take part in external quality assurance programmes (in association with a Cancer Centre).
- A radiologist with a special interest in malignant gynaecological disease, who will take a leading role in imaging.
- A nurse with a special interest in gynaecological cancer, whose role will mainly be to provide information and support for women undergoing assessment for possible cancer.

[1] A Gynaecological Cancer Unit may exist within a single hospital; alternatively, two or more hospitals may collaborate to provide an appropriate range of local services. Both Units and Centres will vary considerably in size but it is envisaged that most Cancer Units would serve populations (men and women, all ages) of at least 200,000 (anticipated range, 100,000 to 400,000); this would usually represent about 50 new referrals for gynaecological cancer per annum. Gynaecological Cancer Centres would serve populations of at least one million, with around 200 new referrals per annum.

Members of this team may have other functions within the hospital; their level of commitment to the Cancer Unit will depend on the size of the population served and the workload involved.

Services provided by the Cancer Unit

- Rapid assessment services for patients with pelvic masses or post-menopausal vaginal bleeding; these services may take the form of dedicated clinics. (See Topic 3, *Ovarian Cancer: Pre-treatment Assessment*, and Topic 5, *Endometrial Cancer: Diagnosis and Pre-treatment Staging*.)

- A dedicated colposcopy service, which would be the responsibility of the lead gynaecologist, for diagnosis and biopsy of cervical lesions. (See Topic 7, *Cervical and Vaginal Cancers: Diagnosis and Staging*.)

- Systems for data collection and audit.

Responsibilities of the Cancer Unit

Initial diagnostic procedures such as clinical examination, biopsies of endometrial, cervical, vaginal and vulval lesions, ultrasound scanning and CA125 tests should be carried out by the gynaecology service at the level of the Cancer Unit (see Topic 3, *Ovarian Cancer: Pre-treatment Assessment*; Topic 5, *Endometrial Cancer: Diagnosis and Pre-treatment Staging*; Topic 7, *Cervical and Vaginal Cancers: Diagnosis and Staging*; and Topic 9, *Vulval Cancer*). The designated lead gynaecologist should normally carry out surgery for early (stage Ia or b, grade 1 or 2) endometrial cancer and for pelvic masses where the risk of malignancy is low (see Topic 3, *Ovarian Cancer: Pre-treatment Assessment*). When initial diagnostic investigations show or strongly suggest the presence of other or more advanced gynaecological cancers, women should be referred immediately to the specialist gynaecological oncology team at the associated Cancer Centre.

Linked services

- Pathology: Biopsy specimens and pathology reports should be sent to the Cancer Centre when women are referred there from the Cancer Unit. Minimum datasets for pathology reporting will be published.[2]

- Chemotherapy: Cancer Units may administer chemotherapy to some women with more advanced gynaecological cancers, provided the basis for this is agreed with the specialist gynaecological oncology team at the Cancer Centre who should make decisions about treatment and provide oncological supervision.

- Psychosocial and psychosexual counselling: The extent to which these are provided at Cancer Units will depend on local circumstances; where they are not available, there should be easy access to these facilities at a Cancer Centre.

- Stoma care: Patients should have access to specialist nurses who can offer assistance with stomas.

[2] The Royal College of Pathologists is publishing a series, "Standards and Minimum Datasets for Reporting Common Cancers". Minimum datasets for gynaecological cancers are in production.

- Lymphoedema treatment: Nurses or therapists with specialist knowledge of lymphoedema should be available at Cancer Units.

- Palliative care: Cancer Units will be responsible for delivery of some aspects of palliative care. The palliative care team should be multiprofessional with a key role for specialist nurses (see Topic 11, *Palliative Treatment and Care*).

How the Cancer Unit team functions

The Cancer Unit gynaecology team should meet regularly, at least once a fortnight, to discuss the management of individual patients. Decisions should follow documented local clinical policy, which should be decided by the team in collaboration with the specialist gynaecological oncology team at the linked Cancer Centre (see below). The team should have adequate support to ensure that all decisions are recorded and communicated to patients and their GPs.

Audit of processes and outcomes, and action stimulated by audit findings, should be discussed in team meetings. Data collection systems should be compatible with those used by the linked Cancer Centre, to facilitate common audit.

The Cancer Centre and the specialist gynaecological oncology team

Women with gynaecological cancers which are less common or more difficult to treat (ovarian cancers, later stage endometrial cancers, cancers of the cervix, vulva or vagina) should be managed by a specialist multiprofessional gynaecological oncology team based at a Cancer Centre. This core team should liaise closely with designated lead gynaecologists at Cancer Unit level.

All members of the Cancer Centre core team should have a special interest in gynaecological cancer. One member should take managerial responsibility for the service as a whole.

Members of the Cancer Centre core team [3]

- 2 gynaecological oncologists (subspecialist gynaecologists who specialise in surgery for gynaecological cancer).

- Radiotherapy specialist (clinical oncologist).

- Chemotherapy specialist (medical oncologist or clinical oncologist).

- Radiologist.

- Histopathologist.

- Cytopathologist.

- Clinical nurse specialist.

[3] Cancer Centres vary considerably in size. These recommendations are illustrative of Centres serving populations of around one million.

How the Cancer Centre team functions

The specialist gynaecological oncology team should meet weekly to discuss the management of individual patients. There should be joint or parallel clinics involving different disciplines, so that individual patients can be seen and discussed by two or more team members together. More than one person may be required to fulfil each role in the team, depending on workload.

The team must maintain close contact with other professionals who are actively involved in supporting the patient or carrying out the management strategy decided by the team. These include the following:

- GP/primary health care team.
- Gynaecologists and pathologists with a special interest in gynaecological cancer, working at the Cancer Unit level.
- Psychiatrist, psychologist or trained counsellor with expertise in cancer and psychosexual problems.
- Cancer genetics specialist.
- Social worker.
- Palliative care team.

Co-ordination between teams

Throughout the care of each patient, there should be a named clinician to whom she principally relates, for example, the gynaecological oncologist in the early stages of the disease and the palliative care physician at later stages. Such arrangements should be explicit and clearly understood by patients and health care professionals, including the primary care team. Patients should be given written information about the members of the team involved in their management.

Close co-ordination is required between the primary health care team, the treatment teams at both Cancer Unit and Cancer Centre levels, the palliative care team, and patients and their families. The overall clinical lead will vary, depending on the patient's needs.

Decisions about management should follow local clinical policy which should be demonstrably evidence-based. All members of teams should be involved in discussions on local policy decisions and auditing adherence to them.

All teams must have adequate support to ensure that all decisions are recorded and communicated promptly to patients and all those outside the core team - for example, GPs and other professionals - who require, or may benefit from, information about decisions made about the care of particular patients.

Teams should be jointly responsible for audit and participation in clinical trials. Audit of outcomes, and action such as training needs which may be stimulated by audit findings, should be discussed in team meetings.

There is no reliable research which can be used to define minimum acceptable workloads. The number of patients seen over a year should be sufficient to allow each team to function efficiently and to allow sensible analysis and interpretation of audit results.

B. Anticipated Benefits

In gynaecological cancer, treatment by specialist teams is likely to improve survival and quality of life. Specialisation at the level of the Cancer Centre allows women with rarer or more challenging cancers to be treated by clinicians who see enough cases to develop the expertise necessary to manage the disease effectively.

Team working facilitates co-ordinated care. Patients managed by teams are more likely to be offered appropriate treatments and to receive continuity of care through all stages of the disease. Specialist nurses in multiprofessional teams can reduce patients' distress, increase satisfaction, and improve information flow to patients.

C. Evidence

The research evidence for much of this area is limited; due to the nature of the questions, randomised controlled trials (RCTs) are unlikely to be undertaken and none has been identified. However, there have been some good quality observational studies which provide consistent evidence, and these are backed up by audit studies.

Specialist treatment

Good quality observational studies, notably a major prospective study in Scotland, have found that the survival of women with ovarian cancer is significantly improved when they are managed by gynaecologists sub-specialising in cancer.(B) Specialist gynaecological oncologists are more likely to carry out appropriate and adequate surgery and offer effective adjuvant therapies.(B) Audits of cervical cancer management have shown that non-specialists may be less likely to use appropriate investigations, may under-estimate the stage of the cancer, and may provide sub-optimal treatment.(B)

Treatment in teaching hospitals is associated with more appropriate management and better survival for women with ovarian cancer in Scotland.(B) The same is true for cervical and endometrial cancer in south east England, where hospitals which deal with more patients also have better outcomes.(B) Audit-based studies suggest that hospitals which deal with more cases of cervical cancer and ovarian cancer, or where management is by specialists, are more likely to offer appropriate treatment and stage adequately. Inappropriate care is associated with reduced survival.(B)

Currently, many women are treated by non-specialist gynaecologists who deal with each type of cancer infrequently, perhaps only once or twice a year. For example, in one county in the south east of England, 10 of the 15 surgeons treating women with ovarian cancer and 12 of 16 treating women with cervical cancer carried out four or fewer operations on these women in 1997.(B) The figures for vulval cancer are even lower, with many surgeons carrying out only one procedure in a year. This level of workload is unlikely to permit surgeons to develop or maintain the expertise required for optimum treatment.

Evidence from a Citizen's Jury suggests that women are willing to travel to maximise the quality of the care they receive, and that proximity of the place of treatment to their home is considered far less important than the clinicians' expertise.(C)

Multiprofessional teams

Management in a multidisciplinary clinic has been found to lead to more appropriate treatment and better survival for women with ovarian cancer in Scotland.(B) However, it is not possible to separate the specific effects of team working from those of specialised care and more appropriate use of platinum-based chemotherapy.

The benefits offered by nurses specialising in supporting women with gynaecological cancers have not been investigated in any study in the UK, where there are very few such nurses. Anecdotal evidence suggests that the support they offer is appreciated by patients and that their contribution can lighten oncologists' workloads.(C)

How the teams function

There is strong general evidence that the use of clinical guidelines can improve the process and outcome of care. Local adoption of guidelines of good quality, incorporating the best up-to-date evidence and addressing relevant aspects of care, can lead to better outcomes for patients.(A)

There is audit evidence from two different areas that the management of women with gynaecological cancer of any site often fails to follow national guidelines or agreed local protocols and that sub-optimal treatment may be given to around half of these women. Under-treatment is associated with impaired survival, whilst over-treatment can cause avoidable morbidity and is wasteful.(B)

There is audit and anecdotal evidence of problems in interprofessional communication; such problems have been linked with complaints and litigation.(C)

D. Measurement

Structure

- Agreed, evidence-based, documented local clinical policy on the management of gynaecological cancers.
- Appropriate teams in place at accredited centres and units.

Process

- Evidence of regular team meetings at both Cancer Unit and Centre.
- Use of locally agreed clinical policies and guidelines.
- Number of procedures carried out for each type of cancer by individual surgeons.
- Proportion of women treated by appropriate personnel.
- Proportion of women whose tumours are fully staged.

- Audit of outcomes of treatment, including detailed information on case-mix.

- Participation in the National Gynaecological Pathology External Quality Assurance Scheme.

Outcome

- 5-year survival rates for each type of gynaecological cancer, adjusted for case-mix.

- Morbidity, assessed prospectively.

E. Resource Implications

- Resources may be required to increase the numbers of specialist staff (for example, gynaecological oncologists and specialist nurses). Extra work sessions will be required, particularly for pathologists.

- The re-structuring of services in line with Calman-Hine proposals and configuring specialist teams may involve significant costs.

The cost implications of the reorganisation of cancer services were estimated from a study of 12 potential Cancer Centres in four regions and a more detailed analysis of cost data from three case studies.

At some Cancer Centres the current service is similar to what is recommended, few additional referrals are expected, and little change is anticipated. However, in the majority of Cancer Centres, the surgical and pathology workload for gynaecological cancer will rise substantially, with large increases in referrals from associated Cancer Units. The costs of chemotherapy and radiotherapy are not expected to rise, since provision is already generally centralised (the impact of paclitaxel is not examined here).

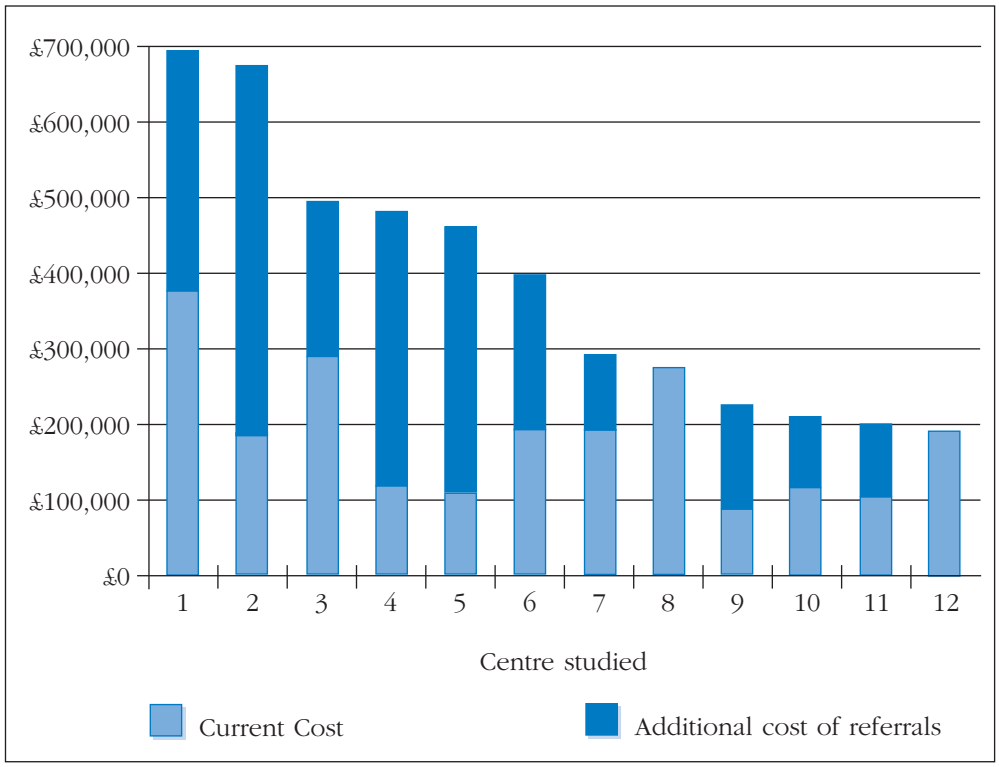
Annual costs for surgery at a typical Cancer Centre for all gynaecological cancers are estimated to double on average (an estimated average rise of almost £200,000). The variety is substantial and the largest increase estimated is up to £490,000.

The results for the most detailed case study showed an additional Cancer Centre cost estimate of £325,000 for primary surgical work (an 85% increase in gynaecological cancer surgery costs and an 8% increase in total gynaecology costs). These costs could be under-estimates because they assume that post-surgical admissions will remain at Cancer Units, when in fact some are likely to occur at Cancer Centres.

Releasing costs from units may be difficult. Primary surgical treatment represents around 4% of gynaecology costs and inclusion of post-operative, palliative and terminal care costs increases this to 7%. Transfer of work to Cancer Centres will not permit reductions in medical staff or hospital ward provision. Cost reductions will depend on local situations.

The development of the integrated teams is not expected to incur additional costs beyond those shown above. The key elements of the Cancer Centre team structure were in place in the two most detailed case studies examined. One Cancer Centre

Cost of surgical referrals of gynaecological cancer to centres



had submitted a business case which included figures of the same order as those given here. For Cancer Unit teams, discussions suggested that the key steps of designation of existing staff and assignment of responsibilities are broadly cost neutral.

For aspects such as palliative care, nursing support and audit, much of the infrastructure has been developed following earlier cancer guidance. Since gynaecological cancers represent a small proportion of all cancers, these recommendations have few additional cost consequences in these areas.

The Patient's Perspective

2

Gynaecological cancer can precipitate a range of emotional and relationship problems in addition to the distress that is common to cancers of any site. It may leave women unable to conceive or bear children and can cause lasting damage to sexual experience and relationships. Psychological aspects of care are therefore particularly important.

A. Recommendations

(i) Minimising delay

Delay between initial suspicion of cancer and treatment, and particularly between initial assessment at local hospitals and referral to specialist centres, should be kept to a minimum. The establishment of rapid assessment services for women with symptoms such as abnormal vaginal bleeding (see Topic 1, *Specialist Services and Multiprofessional Teams*) is likely to reduce delay.

(ii) Effective communication

Health care professionals must be sensitive to potential problems with communication and individuals who provide clinical care should have training in communication and counselling skills. Clinical staff need to be aware that patients often find it difficult to take in information given during the consultation, especially just after receiving bad news. Women should be given adequate time to reflect and opportunities to discuss treatment options before making decisions.

Treatment for gynaecological cancers can lead to permanent damage to pelvic organs and precipitate menopause. With early cervical cancer in particular, different types of treatment may be equally effective for control of the disease but effects on sexual and reproductive function are likely to differ. Clinicians should encourage women to make their views and personal priorities clear, and take account of these when they offer proposals for treatment.

(iii) Clear information

Women with cancer should always be given sufficient information to enable them to contribute to decision-making if they wish to do so. At every stage, they, and when appropriate, their partners or relatives, should be offered clear, full and prompt information in both verbal and written form. This should include information about the disease, diagnostic procedures, treatment options and their effects (including potential adverse effects) and as far as possible, a realistic assessment of anticipated outcome. Sexually active patients and their partners should be offered specific information about possible effects on their relationship.

While it should be assumed that most women will want to be kept fully informed, the amount and timing of information should be consistent with individual patients' desire for information. All patients should receive both individual support and

guidance, and well-produced information leaflets (such as those published by CancerBACUP[4]). Patients' preferences should take precedence over the views of relatives or carers.

Patients and their partners or carers should also be given verbal and written information about sources of social support and practical help, such as local support groups and disability and benefits helplines. This information should be provided in appropriate languages.

(iv) Psychosocial support

Psychosocial support should be available at every stage to help patients and their families to cope with the effects of the disease and its treatment. From the time of diagnosis, each patient should have access to a named nurse who has been trained in counselling patients, who has specialist knowledge of cancer, and who can offer continuity of care. Clinical staff, particularly specialist nurses, should have training to enhance their ability to recognise the psychological needs of patients and to deal with them appropriately.

Patients should be encouraged to bring a partner, relative or close friend to provide support at diagnostic clinics and appointments at which distressing news may be communicated.

Adequate provision should be made to ensure that women have privacy and are able to maintain their dignity. Health service staff must be sensitive to potential embarrassment and to the needs of women from cultures with strong taboos about female sexuality and nudity.

Psychosocial support is also important for carers looking after women with advanced cancer at home. The primary and palliative care teams have particularly important roles in ensuring that the needs of both patients and carers are identified and met.

(v) Psychosexual counselling

All women who have treatment that is likely to affect sexual activity (in particular, radiotherapy or surgery to the cervix, vagina or vulva) should be aware that advice is available on minimising adverse effects on their sexual experience and relationships. Specialist interventions should be available for women and their partners to help them to understand and cope with the effects of treatment on sexual relationships.

B. Anticipated Benefits

(i) Minimising delay

Reducing delay will reduce women's anxiety. While it may also permit earlier treatment, it is not clear whether this has a significant impact on survival.

(ii) Effective communication

Effective communication is crucial to good relationships and to ensure that the outcomes of treatment are optimal for the women concerned. Good

[4] CancerBACUP's Publication Department can be contacted on 0171 696 9003. A limited selection of information leaflets for patients with gynaecological cancer (such as *Pelvic Radiotherapy: what you need to know*) is available through the NHS Responseline on 0541 555 455.

communication between health service staff, patients and their families promotes co-operation, minimises misunderstanding, anger and anxiety, and enhances satisfaction with care.

(iii) Clear information

Provision of more and better information would meet the most common complaint made by cancer patients and their carers. Information reduces fear and anxiety, allows patients to express preferences about treatment outcomes and options, and can reduce treatment-related problems.

(iv) Psychosocial support

Psychological morbidity can be reduced by effective support. Psychosocial interventions can reduce pain and distress due to physical symptoms and may improve survival.

(v) Psychosexual counselling

Psychosexual counselling can help women and their partners to cope with sexual and relationship problems that can follow diagnosis and treatment of gynaecological cancer, and increase the proportion of women who remain sexually active after treatment.

C. Evidence

(i) Minimising delay

For 46% of women with cervical cancer and 30% with endometrial cancer, there are delays of six months or more between the onset of symptoms and the beginning of treatment. This may mean that the cancer develops to a higher stage. There is no evidence, however, that survival is impaired by delays of up to three months.(B)

Women's anxiety increases with increasing time between suspicion of cancer and the beginning of treatment. Delay between referral from Cancer Unit to Cancer Centre, when women are aware of the probable diagnosis and are awaiting specialist assessment and treatment, is likely to be particularly distressing.(C)

(ii) Effective communication

There is considerable evidence that problems with communication between doctors and patients can cause unintended distress.(B) For example, women report that they are often unable to take in information or to participate effectively in discussions held immediately after receiving a diagnosis of cancer. A taped or written record of the consultation can help by allowing patients to consider the information during subsequent days and by facilitating discussion with friends or relatives.(A) However, a taped record of the consultation can cause increased distress, particularly to patients with poor prognoses.(A)

(iii) Clear information

A variety of studies have shown that over 90% of women with cancer want full and clear information; younger, more highly educated women are particularly likely to want detailed information.(B) This reduces anxiety and increases satisfaction with services. Although almost all women wish to participate in some way in decision-making about treatment, few are given sufficient information to do so effectively. Many women also want their partners to be given more information, particularly about the effects of treatment on sexual function.(B)

There is specific evidence that women undergoing chemotherapy for recurrent ovarian cancer do not receive adequate information. A UK study of 62 women found that none was well informed about renal or neurological toxicity, although 46% knew about hair loss and 88% were well informed about nausea and vomiting. These women wanted access to a senior nurse who could give support and advise on practical matters. Written information about chemotherapy for gynaecological cancers is well received; in a pilot project evaluating such information, all 12 patients said they wanted it.(B)

A recent study assessed patient information materials about ten health problems (not including cancer). The results give cause for concern about the quality of information available.(B)

(iv) Psychosocial support

Women who have been treated for gynaecological cancers are prone to problems with social adjustment and depression, and most are anxious about recurrence.(B) A study of women who had undergone radical pelvic surgery found that most would have liked a relative or friend present when bad news was broken and many would welcome more emotional support.(B) There is consistent evidence for cancer patients in general that a variety of cognitive and behavioural interventions can be beneficial. Techniques such as relaxation training and education/information accompanied by counselling can reduce side-effects of therapy and alleviate psychological and functional disturbances.(A)

(v) Psychosexual counselling

Sexual problems including loss of confidence, loss of desire, loss of capacity for arousal and pleasure, vaginal shortening and atrophy, and pain associated with intercourse, are experienced by the majority of women who have been treated for gynaecological cancer; two thirds to three quarters of women treated by radical pelvic surgery or radiotherapy for cervical cancer suffer from such problems.(B) While radiotherapy is generally more likely to lead to sexual problems than surgery, women who have undergone surgery for vulval cancer report very limited capacity for sexual arousal. Younger women are especially vulnerable to psychosexual problems and problems with body image.(B)

A US study found that individual counselling from the time of diagnosis halved the probability that women's sexual activity would cease or be reduced. Only 20% of those who had not been counselled reported levels of sexual activity as high as before diagnosis, compared with 59% of those who had received counselling. Differences between groups remained significant a year later.(B)

D. Measurement

Structure

- Providers should be able to demonstrate the availability of appropriate and adequate verbal and written information, both about gynaecological cancers and their treatment in general, and about each patient's individual situation and options.

- Providers should demonstrate provision of services, including the availability of suitably trained staff, to meet the psychosocial and information needs of patients.

- Providers should demonstrate that psychosexual counselling is available for all women with gynaecological cancer and their partners.

Process

- Evidence that patients and their families/carers receive information and support from suitably trained staff.

Outcome

- Surveys of women's experiences should be carried out by providers to assess the adequacy of each component of patient-centred care.

E. Resource Implications

- Resources will have to be made available for the provision of, and where necessary production of, information and educational material for women with gynaecological cancer.

- Additional resources are likely to be required to allow sufficient staff time for provision of psychosocial, psychosexual and educational support for patients.

- Additional training in communication skills is likely to be necessary for nurses and other clinical staff.

Ovarian Cancer: Pre-treatment Assessment

A. Recommendations

Routine screening of women in general, or women thought to be at higher risk because of a family history of ovarian cancer, is not currently recommended; randomised trials are in progress to assess the effectiveness of screening.

Women who may be at higher risk should be offered referral to a cancer genetics clinic. Higher risk should be defined as in the inclusion criteria for the ongoing UKCCCR trial of ovarian cancer screening, which are associated with a lifetime risk of at least 15%.[5] Prophylactic oophorectomy should be available for women at high risk if they wish to undergo this procedure.

GPs or other clinicians, including surgeons, who suspect that a woman could have ovarian cancer should refer her to the designated gynaecologist in a Cancer Unit for assessment. Women who present as emergencies should normally be stabilised and referred. All women with pelvic masses should be referred to a rapid assessment out-patient clinic at a Cancer Unit; a diagnosis of cancer should not be excluded on the basis of clinical impressions alone.

Clinicians should be alert to the possibility that vague, persistent gastro-intestinal symptoms such as bloating, abdominal discomfort and irregular bowel habit, or pelvic discomfort or backache with weight loss, could be due to ovarian cancer, and any woman with such symptoms should have a careful pelvic examination. This should be included in documented local clinical policy for the management of women with persistent unexplained abdominal pain.

Assessment at the Cancer Unit should include full abdominal and vaginal examination, transvaginal ultrasound and CA125 assessment. Women with pelvic masses which are judged likely to be malignant on the basis of age, raised CA125 levels, and ultrasound findings, should be referred without delay to a specialist multiprofessional gynaecological oncology team at a Cancer Centre (see Topic 1, *Specialist Services and Multiprofessional Teams*).

[5] Eligibility criteria are as follows: the individual must be over the age of 25 and a first degree relative of an affected member of a high risk family, defined by the following criteria:

1. Two or more individuals with ovarian cancer who are first degree relatives.
2. One individual with ovarian cancer and one with breast cancer diagnosed before the age of 50 who are first degree relatives.
3. One individual with ovarian cancer and two with breast cancer diagnosed before the age of 60 who are connected by first degree relationships.
4. An affected individual with a mutation of one of the genes known to predispose to ovarian cancer.
5. Three individuals with colorectal cancer with at least one diagnosed below the age of 50 years, as well as one case of ovarian cancer, and all these individuals are connected by first degree relationships.

B. Anticipated Benefits

Prompt assessment is important to identify women with ovarian cancer so that they can be referred for specialist treatment. Prompt assessment is likely to reduce women's anxiety, whilst appropriate referral is likely to lead to improved survival and increase the chance that the fertility of younger women can be preserved.

C. Evidence

Although ovarian cancer can be detected in asymptomatic women using CA125 and/or ultrasound, a recent systematic review has found no evidence that screening to identify and treat such women affects survival.(B) Three randomised trials are currently in progress to determine whether screening can reduce mortality.

Women with one first-degree relative with ovarian cancer have twice the average risk of developing the condition - about a 3% lifetime risk. When more than one relative is affected, the risk of developing ovarian cancer between the ages of 45 and 75 is 14%.(B) Women with a strong family history of ovarian cancer may have genetic mutations such as BRCA1 which can be detected; this information allows the risk of ovarian cancer to be estimated so that women can make decisions on prophylactic removal of the ovaries. There is no reliable evidence on which to assess risk reduction through prophylactic oophorectomy.

An uncontrolled study of screening in this higher risk group is being carried out by the UKCCCR.

In women with pelvic masses, it is usually possible to differentiate between benign and malignant cysts by combining transvaginal ultrasound findings, the CA125 level and the patient's age. Studies which combined these measures have reported sensitivity ranging from 78% to 89% and specifity ranging from 87% to 99%.(B) Around a quarter or one-third of women investigated by gynaecologists for adnexal masses are likely to have ovarian cancer.(C)

Identification of ovarian cancer can be particularly difficult when the symptoms are vague and this can lead to long delays in diagnosis.(C) A Swedish study found that although diagnosis was usually recorded within a month, delays could amount to as much as a year from the onset of symptoms.(B)

D. Measurement

Structure

- A system for referring women for investigation and treatment according to documented local clinical policy, which minimises delay between initial investigation and treatment.

Process

- Proportion of women with ovarian cancer referred to the Cancer Centre before surgery.

- Time from initial consultation to referral and treatment.

E. Resource Implications

- Resources are likely to be required to provide cancer genetics services for women at higher risk.

- Resources may be required to set up rapid assessment clinics for investigation of pelvic masses. These may be combined with post-menopausal bleeding clinics (see Topic 5, *Endometrial Cancer: Diagnosis and Pre-treatment Staging*).

- Additional resources may be required to improve access to transvaginal ultrasound.

Ovarian Cancer: Treatment

Decisions about the management of women with ovarian cancer should be made at Cancer Centres.[6] Surgery is the cornerstone of curative treatment, but for most women with advanced disease, complete removal of the tumour is not possible. Chemotherapy can increase the life-expectancy of women with ovarian cancer. Radiotherapy has no role in the primary treatment of ovarian cancer.

A. Recommendations

4

Surgery for ovarian cancer should be carried out by specialised gynaecological oncologists at Cancer Centres. In every case, detailed records should be kept of surgical findings, including residual disease, cancer stage and histological grade.

Women who present as emergencies should, whenever possible, be stabilised and transferred immediately to Cancer Centres if ovarian cancer is a probable cause of their symptoms. When this is not possible, or when ovarian cancer is discovered at the time of surgery, surgeons should seek advice from specialists.

The aim of surgery should be to remove as much cancer tissue as possible (optimum debulking) and to stage the disease accurately. When optimal debulking (to nodules of <1cm) is not possible at the time of initial surgery, a second attempt may be appropriate after three cycles of chemotherapy. In this situation, patients should be considered for entry into the MRC OV06 trial.[7] A baseline CT scan may assist in informing management after surgery.

Chemotherapy is appropriate after surgery for the majority of women. However, there are many areas of uncertainty about optimum chemotherapy and multi-centre randomised controlled trials such as the MRC ICON series should be supported. Responsibility for chemotherapy should be taken by the specialist gynaecological oncology team at the Cancer Centre but chemotherapeutic agents can be delivered in Cancer Units under the overall direction of the Cancer Centre.

Patients should be given realistic information about expected benefits and adverse effects of chemotherapy and should be encouraged to contribute to decision-making unless they make it clear that they do not wish to be involved.

Chemotherapy should not normally be offered to women with Stage I ovarian cancer unless there are indicators suggesting poor prognosis, such as malignant

[6] The existing supra-regional choriocarcinoma service is not affected by this guidance.

[7] MRC OV06: A randomised trial of interval debulking surgery for ovarian cancer. (Trial coordinator: Julia Bland, Cancer Division, MRC Clinical Trials Unit, Cambridge.)

ascites. Women for whom the potential benefit of chemotherapy is uncertain should be encouraged to participate in the MRC ICON1 trial.[8]

Women with more advanced ovarian cancer should be offered appropriate chemotherapy. Paclitaxel plus carboplatin should be standard therapy unless there are particular concerns about toxicity in relation to the individual patient's fitness; in these circumstances carboplatin alone may be appropriate. These recommendations should be reviewed when the results of ICON3 (see below) are mature.

Women with recurrent ovarian cancer should be offered a further course of chemotherapy. The choice of drug depends on the agent(s) previously used and the time-period before relapse. The possibility of chemotherapy-resistant disease should be considered if women fail to respond to two different types of chemotherapeutic agent.

Chemotherapeutic agents require special care in delivery and dealing with adverse effects. There should be written protocols on administration of chemotherapy and on the management of complications and toxicity. Chemotherapy should be given in a designated daycase area in units or centres where close supervision by oncologists and chemotherapy nurse specialists is available, in accordance with Joint Council for Clinical Oncology (JCCO) guidelines.[9] There should be expert pharmacy and 24-hour laboratory support.

Women receiving chemotherapy should have access to emergency care, information and advice from oncology trained staff on a 24-hour basis. They should be given written information on appropriate action for dealing with side-effects of chemotherapy and should be specifically warned, both verbally and in writing, of the particular risk of infection about 10-14 days after beginning chemotherapy. Any woman with signs or symptoms that could be due to infection must be assessed without delay.

B. Anticipated Benefits

When ovarian cancer is diagnosed early (stage I), surgery alone can lead to survival rates of over 80% at five years. Unfortunately, about three quarters of patients are at stage II to IV at the time of diagnosis; for these women, survival time is likely to be improved by expert surgery followed by appropriate chemotherapy. 5-year survival, in European centres which report to FIGO has increased from 27% in 1958-62 to 42% in 1990-2.

C. Evidence

About half of women with ovarian cancer have stage III disease at the time of surgery; in most of these, the tumour has spread beyond the pelvis and into the lymph nodes (stage IIIc). Data from a group of European centres (FIGO) show that fewer than 15% of women have low-risk, early stage (Ia or Ib) disease at the time of initial surgery.(B)

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[8] MRC ICON1: A randomised trial of adjuvant chemotherapy in early ovarian cancer. (Trial coordinator: Josie Sandercock, Cancer Division, MRC Clinical Trials Unit, Cambridge.)

[9] Joint Council for Clinical Oncology. *Quality Control in Cancer Chemotherapy*. London: The Royal College of Physicians and The Royal College of Radiologists, 1994. An update of these guidelines should be available later this year (1999).

Specialists achieve more accurate staging, and outcomes are better after specialist treatment (see Topic 1, *Specialist Services and Multiprofessional Teams*).(B) The quantity of tumour remaining after surgery is a major determinant of prognosis, and optimum surgical debulking - removal of as much cancer tissue as possible - improves survival.(A) Specialists are able to achieve better levels of debulking.(B) Interval debulking, which involves a second surgical intervention to remove remaining tumour after chemotherapy, has been found to improve survival by six months.(A)

Some studies have demonstrated tumour-positive lymph nodes in women whose disease appeared to be limited to the ovary, and such women could be expected to benefit from chemotherapy. However, a large retrospective study suggests node biopsy is not associated with improved outcome in stage I and II disease.(B)

No evidence was identified to suggest that chemotherapy offers any benefit for women with stage I disease. The MRC ICON1 trial may clarify the issue of the value of chemotherapy for women with stage I disease; initial results are expected to become available from the year 2000.

Four meta-analyses, using data from 5,667 individual patients with advanced ovarian cancer in 37 randomised controlled trials, provide quantitative evidence on the comparative effectiveness of different chemotherapeutic agents and combinations. These meta-analyses do not include any trials in which taxanes were used.

The results suggest that platinum-based combination chemotherapy offers the greatest survival benefit. This was found to be superior to alternative regimens in each comparison reported, but the only statistically significant difference was between platinum-based chemotherapy and a similar drug combination which did not include platinum (hazard ratio 0.88, 95% CI: 0.79 to 0.98). This is equivalent to a 5% improvement in absolute survival at 5 years - from 25% to 30%.(A)

There was no evidence of any difference in terms of survival between cisplatin and carboplatin (hazard ratio 1.02, 95% CI: 0.93 to 1.12). This finding is supported by the recent results of the MRC ICON2 trial. This trial found that carboplatin was better tolerated than the combination of cyclophosphamide, doxorubicin and cisplatin, with no survival difference between the two regimens.(A)

Paclitaxel-cisplatin or paclitaxel-carboplatin has been compared with a cisplatin-based control for first-line chemotherapy in advanced ovarian cancer in four randomised trials (GOG111, OV10, GOG132, ICON3). Results have only been formally published for GOG111, although mature data are available for OV10 and GOG132.

Two studies, GOG111 and OV10, report similar improvements in survival, with hazard ratios of 0.61 and 0.71 (95% CI: 0.47 to 0.79 and 0.57 to 0.89, respectively) in favour of paclitaxel-cisplatin when compared with cyclophosphamide-cisplatin. All the women in GOG111 and the majority in OV10 had macroscopic residual disease after surgery. Those who received paclitaxel-cisplatin survived for an additional year. (A)

The third trial, GOG132, which compared paclitaxel-cisplatin with a higher dose of single agent cisplatin, shows no apparent benefit associated with paclitaxel. However, many patients in this trial crossed over to paclitaxel before the disease progressed, which is likely to obscure differences between treatment groups.(A)

The fourth trial, ICON3, includes over 2,000 women. It compares paclitaxel-carboplatin with carboplatin alone or with cyclophosphamide, doxorubicin and cisplatin (CAP). Preliminary data,[1] based on a median follow-up of 18 months, have now been released, but these are not sufficiently reliable to guide policy or practice.

Paclitaxel-carboplatin is as effective as paclitaxel-cisplatin but is better tolerated. (A)

Second-line chemotherapy can produce worthwhile responses but the choice and effectiveness of treatment depends on the length of remission after first-line chemotherapy. Women whose symptoms recur more than 12 months after responding to a course of platinum-based chemotherapy are likely to respond again to similar agents. However, in some women, the disease does not appear to respond to any form of chemotherapy.(B)

A UK cost analysis estimated the cost of paclitaxel and cisplatin at £10,427 per patient (including treatment of adverse effects), compared with £2,059 for carboplatin alone. The total cost of treatment with paclitaxel and cisplatin has been calculated to be £7,173 (95% CI: £4,366 to £50,209) per extra life year gained. This analysis was based on the results of one trial. An update of the analysis, incorporating evidence from recent trials, estimates a cost per life year in the range £7,000 to £11,000 and a cost per progression-free year of between £20,000 and £22,000.

Radiotherapy has not been found to be effective for the primary treatment of ovarian cancer.(A)

D. Measurement

Structure

- A clear access route to specialist gynaecological oncologists.
- Availability of specialist non-surgical oncologists and appropriate support.
- A documented local clinical policy for the administration of chemotherapy and the management of complications and toxicity.

Process

- Proportion of women treated by specialist gynaecological oncologists.
- Full staging information for each woman treated.
- Proportion of women with stage II or more advanced ovarian cancer who receive platinum-based chemotherapy.

Outcome

- 5-year survival rates, adjusted for case-mix.
- Morbidity after treatment.

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[1] Preliminary data were presented at the American Society of Clinical Oncology (ASCO) conference in May 1999. These early data inevitably have serious limitations:

- The duration of follow-up is too short to provide reliable results, particularly for patients in good-prognosis groups.
- ICON3 is potentially large enough to permit subgroup analysis when mature data are available, but as yet such analysis is not reliable.

E. Resource Implications

- Cost of training specialist gynaecological oncologists.
- The introduction of newer chemotherapeutic agents for routine treatment of ovarian cancer could greatly increase the costs.
- Based on the costing work (described in Section E of Topic 1, *Specialist Services and Multiprofessional Teams*), increased referrals to the Cancer Centre are estimated to increase annual costs for surgery for ovarian cancer by about 135% (range: £0 to £210,000).

Endometrial Cancer: Diagnosis and Pre-treatment Staging

Endometrial cancer is most common amongst post-menopausal women and the main symptom is vaginal bleeding. 8-10% of women with post-menopausal vaginal bleeding have cancer.

A. Recommendations

Women with post-menopausal vaginal bleeding should be referred to the gynaecological assessment service at the Cancer Unit. (See also, Topic 7, *Cervical and Vaginal Cancers: Diagnosis and Staging*.)

Initial investigation should be carried out in rapid assessment out-patient clinics, which may take the form of abnormal bleeding clinics; possibly combined with pelvic mass clinics (see Topic 3, *Ovarian Cancer: Pre-treatment Assessment*). Women with post-menopausal vaginal bleeding should have transvaginal ultrasound to assess the thickness of the endometrium.

Transvaginal ultrasound imaging should be used to assess the depth of myometrial invasion - that is, the extent to which the tumour penetrates the muscle of the uterus - and thus, the risk of lymph node metastasis. If the scan shows tumour in the outer half of the myometrium, the patient should be referred for specialist treatment at a Cancer Centre.

Biopsy, normally using the Pipelle aspirator, should be carried out if the endometrium is over 5mm thick. Diagnostic dilatation and curettage (D&C) should be used only when out-patient biopsy is unsuccessful, and is particularly inappropriate for women under 40, amongst whom the prevalence of endometrial cancer is very low.

The tumour grade can be assessed by pathological examination of biopsy samples. This information should be used with the ultrasound results to select women with stage Ia or b, grade 1 or 2 disease for treatment at the Cancer Unit (about 40% of cases). Women who are judged to have more advanced or higher risk cancers (stage Ic; stage I, grade 3 and higher; and those with morphological or other features associated with poor prognosis) should be referred to Cancer Centres.

Magnetic resonance imaging (MRI) should be available for pre-treatment staging at Cancer Centres.

B. Anticipated Benefits

Out-patient investigation of abnormal vaginal bleeding can minimise both costs and delays without impairing outcomes. Transvaginal ultrasound scanning is a safe, low-cost and effective method for excluding endometrial cancer. This technique allows over three-quarters of women to be reassured immediately. Many invasive procedures can be avoided by routine use of transvaginal ultrasound. Dedicated out-patient clinics for women with abnormal vaginal bleeding can provide a one-stop investigation service which reduces delays in diagnosis. Minimising the use of D&C, an in-patient or day case procedure normally carried out under general anaesthetic, is likely to reduce costs and risk to women. Selection of women with cancers with good prognosis allows them to be treated safely in local hospitals.

C. Evidence

Transvaginal ultrasound is highly reliable for the detection of endometrial cancer. For women with post-menopausal vaginal bleeding, its negative predictive value - its accuracy for excluding a diagnosis of cancer - can be close to 100%.(B)

A range of sampling devices can be used to biopsy the endometrium; these appear to be equally accurate, giving a correct diagnosis of cancer in over 80% of cases, but they vary in patient acceptability. The Pipelle sampling device is as accurate as the Novak curette but it causes less pain; the Novak, the Vabra, and the Karman curette are as accurate as diagnostic dilatation and curettage (D&C).(A) Invasive investigations such as D&C are seldom indicated for women under the age of 40, who are very unlikely to have endometrial cancer, but may be necessary for older women when other methods cannot be used.(C)

80% of women with post-menopausal vaginal bleeding can be safely and effectively assessed as out-patients, but an audit in Scotland reported large variations in the use of out-patient investigation.(B) This project included an economic analysis which showed that out-patient biopsy cost up to £200 less per patient than D&C or hysteroscopy under general anaesthetic.(B)

The depth of myometrial invasion is closely correlated with lymph node involvement and thus, the stage of the cancer. Transvaginal ultrasound has a sensitivity of 61% and specificity of 89% for detecting tumour invasion extending through more than half of the myometrium.(B) MRI is more sensitive than ultrasound or CT for assessing myometrial invasion and tumour spread beyond the uterus, but its cost-effectiveness is unclear. The diagnostic value of MRI in the pre-operative assessment of endometrial cancer will be clarified by an ongoing MRC trial (A Study in the Treatment of Endometrial Cancer - ASTEC), which is not expected to be completed before 2002.

D. Measurement

Structure

- A system for referring women for investigation, treatment, and where appropriate further referral, which minimises delay between initial investigation and treatment.

Process

- Time from initial consultation to referral and treatment.

E. Resource Implications

- Investigation of post-menopausal vaginal bleeding in out-patient clinics could reduce costs.

- Minimising the use of D & C may reduce costs.

Endometrial Cancer: Treatment

A. Recommendations

Endometrial cancer of stage Ia and b, grade 1 or 2 should normally be treated by surgery (total abdominal hysterectomy (TAH) and bilateral salpingo-oophorectomy (BSO)) at a Cancer Unit. No further treatment is likely to be required.

Women with higher risk tumours (stage Ic, stage I grade 3, stage II and higher, sarcomas) should be treated by specialist gynaecological oncology teams at Cancer Centres. While surgery is appropriate for the majority of these patients, radiotherapy may be used to treat those with advanced disease for whom surgery is considered inappropriate, or when surgery is contra-indicated.

Adjuvant radiotherapy for women with more advanced or higher risk tumours should be discussed by the specialist gynaecological oncology team. Where appropriate, women should be encouraged to participate in the MRC ASTEC trial (see Topic 5, *Endometrial Cancer: Diagnosis and Pre-treatment Staging*), which compares external beam adjuvant radiotherapy with lymphadenectomy (removal of lymph nodes) to no treatment apart from TAH/BSO.

Progestogens should not be used for adjuvant treatment for endometrial cancer. Women should be offered oestrogen replacement therapy if indicated.

Radiotherapy should be offered to women with recurrent endometrial cancer who have not already had pelvic radiotherapy.

B. Anticipated Benefits

Most women with endometrial cancer can be treated by surgery alone with minimal morbidity and high rates of survival (over 75% at five years in major European centres).

C. Evidence

The majority (around 90%) of women with endometrial cancer are treated by primary surgery (TAH/BSO or more extended operations); about half also receive adjuvant radiotherapy. There is no research evidence that confirms that TAH/BSO is the optimum type of operation for early disease; this is based on professional consensus.(C)

5-year survival rates are around 70% overall. Two observational studies suggest that lymphadenectomy may enhance survival, but there is no reliable evidence on when it should be used.(B)

Radiotherapy is used in advanced disease, when surgery is inappropriate or incomplete, and for treating recurrent disease in women who have not previously received radiotherapy. 5-year survival rates after radiotherapy alone are around 40%.(B)

There is wide variability between centres in the use of adjuvant radiotherapy, and no consensus either on which patients should receive this type of treatment, or on the type of radiotherapy (external beam, vault brachytherapy, or both) that should be given.(B) There is currently no reliable research evidence on which decisions may be based.

Although adjuvant radiotherapy is given to most women with high-risk early endometrial cancer, evidence that it improves survival is derived only from non-randomised studies.(B) The optimum use of radiotherapy in women with high-risk tumours is being evaluated in a multi-centre randomised trial (ASTEC, see above). One RCT found that pelvic irradiation, given in addition to vault brachytherapy, reduced the rate of pelvic recurrence but did not improve survival.(A)

Radiotherapy can have lasting adverse effects, including damage to the vagina, bowel and urinary tract. The combination of radiotherapy and surgery (particularly lymphadenectomy) may cause lymphoedema of the legs and lower abdomen.

No evidence has been identified to suggest that primary chemotherapy is beneficial as adjuvant therapy for women with endometrial cancer. Chemotherapy may have a limited role in palliative treatment, but the research evidence for this is weak.(B) A meta-analysis of the results of seven RCTs shows that adjuvant progestogen therapy confers no survival benefit.(A)

D. Measurement

Structure

- A clear access route to the specialist gynaecological oncology team at a Cancer Centre for women with high-risk or advanced endometrial cancer.

- A documented local clinical policy on the use of radiotherapy and on the identification and management of potential adverse effects.

Process

- Proportion of women with higher risk tumours (stage Ic, stage I grade 3, stage II and higher, sarcomas) managed by specialist gynaecological oncologists.

- Full staging information for each woman treated.

- The histopathology data set after hysterectomy should include the following: depth of myometrial invasion, tumour grade and sub-type, presence or absence of hyperplasia in adjacent non-neoplastic endometrium, vascular space invasion, lymph node involvement (when sampled), and the status of peritoneal washings.

Outcome

- 5-year survival rates, adjusted for case-mix.
- Morbidity after treatment.
- Audit of short- and long-term adverse effects of treatment (including fistulae, damage to ureters, bladder and bowel dysfunction, and sexual problems).

E. Resource Implications

- Based on the costing work (described in Section E of Topic 1, *Specialist Services and Multiprofessional Teams*), increased referrals to the Cancer Centre are estimated to increase annual costs for surgery for endometrial cancer by about 90% (range: £0 to £120,000).

Cervical and Vaginal Cancers: Diagnosis and Staging

A. Recommendations

Pre-malignant and non-invasive cervical cancer

Treatment guidelines [10] and quality standards[11] for cervical screening and the management of abnormal smears have been published by the Cervical Screening Programme.

Invasive cervical cancer

Any woman with post-coital or inter-menstrual bleeding, persistent vaginal discharge, or whose cervix looks or feels abnormal, should be referred to a gynaecologist. If the suspicion of cancer is high the woman should be referred directly to the gynaecological assessment service at a Cancer Unit. A cervical smear should not be taken in such cases.

When a patient appears to have superficial invasion, a loop or cone biopsy should be carried out. The biopsy specimen should be examined by a designated pathologist with a special interest in malignant gynaecological disease (see Topic 1, *Specialist Services and Multiprofessional Teams*). Any specimens thought to be squamous cervical cancers at stage Ia1 or higher should also be sent to a specialist pathologist at a Cancer Centre to check the accuracy of staging.

A cone biopsy may be sufficient both for diagnosis and treatment when there is no evidence of tumour at the margins of the sample, but if the biopsy results suggest a higher stage tumour or if there are poor prognostic factors, the patient should be referred to the specialist gynaecological oncology team at the Cancer Centre.

All women whose tumours appear to be more advanced than stage Ia and all those with adenocarcinomas should be referred to the specialist gynaecological oncology team at the Cancer Centre. Magnetic resonance imaging should be available to assess the local extent of early disease.

Vaginal cancer

All women with vaginal cancer should be referred to Cancer Centres for treatment.

[10] Patnick, J and Winder, R. (Eds) *Cervical Screening: A Practical Guide for Health Authorities*. Sheffield: NHSCSP Publication No 7, 1997.

[11] *Quality Assurance Guidelines for the Cervical Screening Programme: Report of a Working Party convened by the NHS Cervical Screening Programme.* Sheffield: NHSCSP Publication No 3, 1996

B. Anticipated Benefits

Specialist pathological assessment and appropriate imaging is essential to determine appropriate treatment. This will reduce errors, particularly over- and under-treatment, thus improving long-term survival, reducing avoidable morbidity, increasing the likelihood that women with early stage cancers may be able to retain their fertility, and reducing the potential impact on sexual relationships.

C. Evidence

Observational studies suggest that appropriate imaging to assess the degree of spread (stage) of cervical cancer before treatment is rarely carried out in the UK.(B) Without this, it is not possible for the surgeon to make an informed judgement about the extensiveness of the operation required to remove the tumour entirely while preserving as much healthy tissue as possible. The need for adjuvant radiotherapy is largely dependent on the stage of the cancer, but also on the completeness of the surgical excision.

Cervical cancers can be evaluated pre-operatively using imaging techniques to assess both the local extent of disease and the nodes, to aid decision-making about treatment.(B) However, a recent audit of over 400 women, referred for radiotherapy after surgery for cervical cancer, found no mention of pre-operative imaging in the notes for 94% of these women.(B)

An audit of management and survival of 469 women with cervical cancer in south east England found records of appropriate staging for only 15.6% of all patients, falling to 7% in non-teaching hospitals without oncology support. 41% were not treated in accordance with protocols that had been agreed by clinicians in the local area. Overall 20% of all women were under-treated and 21% over-treated; of women with stage Ib disease 33% were under-treated and 30% over-treated. Mortality rates amongst those who were under- or over-treated were significantly increased compared with women who received appropriate treatment (hazard ratios of 3.98 (95% CI: 2.30 to 6.89) and 1.71 (95% CI: 0.62 to 4.73) respectively).(B)

Another audit, from the South West Region, also revealed that many patients' notes contained no reference to staging.(B)

D. Measurement

Structure

- A system for referring women for investigation and treatment according to documented local clinical policy, which minimises delay between initial investigation and treatment.

Process

- Time from initial consultation to referral and treatment.
- Adequate information on pathology and staging in data set.

E. Resource Implications

- Additional resources will be required for pathology services and in particular specialist pathologists at Cancer Centres to check biopsy samples.

Cervical and Vaginal Cancers: Treatment

Surgery is appropriate for the majority of women with early cervical cancer. For women with later-stage or bulky cancers, radiotherapy is appropriate and concurrent chemo-radiotherapy using cisplatin should be considered. Vaginal cancer is usually treated with radiotherapy.

A. Recommendations

Cervical cancer

Surgical treatment, usually radical hysterectomy with pelvic lymphadenectomy, should be offered to those women with early invasive cervical cancer who are sufficiently fit to undergo surgery and for whom a cone biopsy is inadequate. This should be carried out by specialist gynaecological oncologists working in Cancer Centres.

Radiotherapy and surgery are equally effective in terms of survival for early stage cancers. Surgery alone should be offered whenever possible, since it is less likely to impair sexual enjoyment, bowel or bladder function. Careful assessment is important before treatment begins, to minimise the number of women who undergo both radiotherapy and surgery; adjuvant radiotherapy (radiotherapy after surgery) should be avoided if possible. When adverse prognostic factors are discovered at the time of surgery or subsequent histopathological review, adjuvant radiotherapy may be appropriate and should be discussed by the specialist gynaecological oncology team. The risks and benefits of each option should be discussed with the patient before a choice is made.

Radical radiotherapy should be offered when surgery is unlikely to remove the tumour completely. Guidelines from the Royal College of Radiologists suggest that unscheduled gaps or prolongation of the total course of treatment should be avoided if possible.[12]

Three new studies from the US suggest that women with later-stage or bulky cervical cancers who are fit enough for combined therapy should be considered for chemotherapy using cisplatin, given concurrently with radiotherapy. This approach to treatment is not currently used in the UK, but the number of patients in the trials and the consistency and size of the benefits reported suggest that it deserves serious consideration.

In all other circumstances, chemotherapy as part of primary treatment should normally be offered only in the context of large-scale randomised controlled trials.

[12] Royal College of Radiologists, *Guidelines for the management of unscheduled interruption or prolongation of a radical course of radiotherapy*. Royal College of Radiologists, London, 1996.

Exenterative surgery should be available for women with recurrent cancer confined to the central pelvis. This is a difficult procedure which requires particular expertise and patients will have to be referred to one of a limited number of specialist centres for treatment. This possibility should be considered by the specialist gynaecological oncology team at the Cancer Centre and its implications discussed with the patient. Radiotherapy may be appropriate for women with recurrent cancer who have not previously had this treatment.

Vaginal cancer

Women with vaginal cancer should be managed by specialist gynaecological oncology teams working in Cancer Centres.

B. Anticipated Benefits

High rates of survival can be achieved by surgery alone in women with early stage cancers. Adverse effects on sexual enjoyment may be reduced when surgery, rather than radiotherapy, is used. Radiotherapy is effective for bulky or later-stage cancers, and new evidence suggests that the use of concurrent chemo-radiotherapy with cisplatin can increase survival rates. Long-term adverse effects of treatment can be reduced by avoiding the combination of surgery and radiotherapy. Women who develop recurrent cancer can sometimes be cured by exenterative surgery or pelvic radiotherapy.

C. Evidence

Audits from the South West Region, the South East and Scotland found that treatment was often inappropriate. Women with stage Ib disease who had inadequate surgery (non-radical hysterectomy) had higher mortality rates than those who had radical hysterectomies.(B)

Randomised trials comparing surgery and radiotherapy for early stage cervical cancers show that survival rates are equally high (around 80%) with either treatment.(A) These two types of treatment have different patterns of adverse effects. Surgery can cause acute morbidity, whereas radiotherapy may cause long-term damage to the bowel, bladder and other pelvic organs, and is likely to reduce capacity for sexual enjoyment. Morbidity is greatest when women undergo both surgery and radiotherapy.

Adjuvant radiotherapy is widely used after radical surgery to reduce the risk of recurrence. Several retrospective studies suggest that it can reduce recurrence in the pelvis, but there have been no randomised studies assessing its effectiveness and there is no clear evidence that it improves survival.(B) For advanced disease, radiotherapy is regarded world-wide as the treatment of choice.(C)

Three recent well-designed randomised trials provide consistent evidence that concurrent radiotherapy and cisplatin-based chemotherapy can lead to high survival rates in women with bulky stage Ib or IIa disease or locally advanced cervical cancer (stage IIb, III or IVa).(A) These trials demonstrated that:

- Concurrent cisplatin-based chemotherapy and radiotherapy (chemo-radiotherapy) significantly improved survival relative to radiotherapy alone in a trial including 369 women who also received adjuvant hysterectomy. The relative risk of progression of disease was 0.51 (95% CI: 0.34 to 0.75) and the relative risk of death was 0.54 (95% CI: 0.34 to 0.86).(A)

- Cisplatin and fluorouracil, given concurrently with radiotherapy (external-beam plus low-dose intracavity brachytherapy) was assessed in a trial including 403 women with high-risk cervical cancer (bulky stage Ib/IIa or stages IIb-IVa). The estimated cumulative rates of survival at five years were 73% (95% CI: 65.7 to 80.3) for patients treated with chemo-radiotherapy and 58% (95% CI: 49.8 to 66.2) for those who had radiotherapy alone.(A)

- Chemo-radiotherapy with cisplatin is more effective than without cisplatin. 526 women with stage IIb-IVa cancers were given cisplatin alone, cisplatin/fluorouracil/hydroxyurea, or hydroxyurea alone, concurrently with external-beam radiotherapy and low-dose intracavity brachytherapy. The relative risks of progression or death over 3 years were 0.57 (95% CI: 0.42 to 0.78) and 0.55 (95% CI: 0.40 to 0.75) for chemo-radiotherapy with cisplatin and cisplatin/fluorouracil/hydroxyurea respectively, compared with hydroxyurea. Cisplatin alone was less toxic than combination chemotherapy.(A)

Meta-analysis of the results of seven RCTs of neoadjuvant chemotherapy for locally advanced cervical cancer shows no significant benefit.(A)

There does not appear to be reliable evidence for the effectiveness of any specific intervention to reduce adverse effects of radiotherapy on the bowel.

Exenterative surgery for carefully selected women with extensive cancer confined to the central pelvis (recurrent cancer of the cervix, vagina or vulva, or extensive primary disease) has been reported to result in 40-45% 5-year survival in two UK series. Morbidity is inevitably high, although it has fallen in recent years.(B)

D. Measurement

Structure

- A clear access route to the specialist gynaecological oncology team at a Cancer Centre.

Process

- Proportion of women for whom full information on cancer stage is recorded.

- The histopathology data set after hysterectomy should include the following: histological type, tumour size, depth of invasion relative to overall wall thickness, vascular space invasion, lymph node status, and surgical margin status - parametrium and vagina.

- Proportion of women appropriately treated in relation to stage.

- Proportion of biopsy specimens with clear margins.

Outcome

- 5-year survival rates adjusted for case-mix.
- Morbidity after treatment.
- Audit of short- and long-term adverse effects of treatment (including fistulae, damage to ureters, bladder and bowel dysfunction, and sexual problems).

E. Resource Implications

- Based on the costing work (described in Section E of Topic 1, *Specialist Services and Multiprofessional Teams*), increased referrals to the Cancer Centre are estimated to increase annual costs for surgery for cervical cancer by about 80% (range: £0 to £100,000).

Vulval Cancer

Vulval cancer is rare and requires highly specialised treatment.

A. Recommendations

GPs and other clinicians should refer any woman with symptoms that could be caused by vulval cancer (persistent itching or ulceration that fails to respond to local treatment, visible abnormalities) to the lead gynaecologist at a Cancer Unit. If biopsy results confirm the diagnosis, patients should be referred on to the specialist gynaecological oncology team at a Cancer Centre for treatment. Extensive biopsies should be avoided.

Surgery is the mainstay of treatment for vulval cancer, irrespective of the age of the woman. It should only be carried out by gynaecological oncologists who specialise in this work. Reconstructive surgery should be available; this may involve other surgical specialities. Groin lymphadenectomy should normally be avoided when the cancer invades to a depth of less than 1mm.

For the small proportion of women who have advanced disease, other treatments (chemotherapy, radiotherapy) may be appropriate.

B. Anticipated Benefits

Referral to a specialist is likely to enhance the probability of appropriate staging and treatment of these relatively rare cancers. Women treated by specialists are more likely to receive adequate surgery with minimum avoidable mutilation.

C. Evidence

Surgery for vulval cancer can be mutilating and may remove all capacity for sexual enjoyment. Preservation of sexual function requires skilled decision-making based on specialist knowledge and experience. Currently, many women receive surgery from gynaecologists who may carry out only one or two of these operations in a year, and who therefore do not have the opportunity to gain the necessary expertise.(B)

Surgico-pathological studies have shown that cancer in the groin nodes is very unlikely when the depth of tumour invasion is less than 1mm.(B)

Specialists achieve more accurate staging in vulval cancer because they are more likely to carry out adequate groin node dissection.(B) When groin nodes are positive, radiotherapy may improve survival.(B)

D. Measurement

Structure

- A system for referring women for investigation and treatment according to documented local clinical policy, which minimises delay between initial investigation and treatment.

- A clear access route to the specialist gynaecological oncology team at a Cancer Centre.

Process

- Time from initial consultation to referral and treatment.

- The histopathology data set for surgical specimens should include the following: tumour size and site, histological type and differentiation, associated features such as condylomata, depth of invasion, vascular space invasion, lymph node status, and surgical margin status.

- Proportion of women treated by specialist gynaecological oncologists.

Outcome

- Adequate information on pathology and staging in data set.

- 5-year survival rates adjusted for case-mix.

E. Resource Implications

- Cost of training specialist gynaecological oncologists.

Post-treatment Support and Follow-up

A. Recommendations

At present, there is no evidence to support routine follow-up for women whose cancer is in remission. However, these women are likely to need aftercare and support during the recovery period after primary treatment, and should have continuing access to appropriate services (see Topic 2, *The Patient's Perspective*).

Care following primary treatment has two distinct aspects:

(i) Identification and management of physical and psychological morbidity following primary treatment.

(ii) Prompt detection of recurrent disease in order that treatment may be initiated as early as possible. This in turn has two aspects: prompt access to treatment for women who experience symptoms suggestive of recurrence, and detection of recurrence in asymptomatic women.

(i) Management of morbidity after primary treatment

Treatment for gynaecological cancers can lead to physical, psychosocial and sexual adverse effects. There should be a documented local policy which ensures that all women who have undergone such treatment can receive help, support and appropriate treatment without delay, and that women and their GPs are given full information about how they can access these services. Provision of such services is likely to be shared between Cancer Units and Centres; local arrangements may vary, but there must be effective communication and co-ordination between different levels.

Women should be informed about specific problems that may develop some time after treatment (such as lymphoedema, bowel or bladder dysfunction) and should have clear routes for access to appropriate specialist help if signs or symptoms appear.

(ii) Follow-up to detect recurrent cancer

All women in remission should be given clear information about symptoms which should prompt immediate return to the team which provided primary treatment. They should have access to advice from a member of the team if they become concerned about possible recurrence. Those for whom radical treatment may be possible should be referred to the specialist gynaecological oncology team at the Cancer Centre, working together in joint or parallel clinics. Treatment of recurrence is discussed in the sections of this manual that deal with specific cancer sites (see Topic 4, *Ovarian Cancer: Treatment*; Topic 6, *Endometrial Cancer: Treatment*; Topic 8, *Cervical and Vaginal Cancers: Treatment*).

Ovarian Cancer

There is no reliable evidence to show that routine follow-up of asymptomatic women after treatment for ovarian cancer improves outcomes. An MRC/EORTC trial (OVO5) to assess the value of monitoring the cancer marker, CA125, in women in complete remission after first-line chemotherapy, is in progress.

Endometrial cancer

Routine follow-up should not be considered mandatory for women who are in complete remission after curative treatment for endometrial cancer. Such women should be informed about the lack of known benefit of follow-up and encouraged to choose whether they wish to attend follow-up clinics. Women should be reassured that recurrence is unlikely three years or more after initial treatment.

Vaginal vault smears should not be used to detect recurrent endometrial cancer.

Cervical, vaginal and vulval cancers

Radical treatment by surgery or radiotherapy can be appropriate for a small proportion of women who develop recurrent disease. Early detection of recurrence and management of such patients will require the skills of the specialist gynaecological oncology team at the Cancer Centre (see Topic 8, *Cervical and Vaginal Cancers: Treatment*).

There is no reliable evidence on which to base recommendations for routine follow-up of asymptomatic women after treatment for cervical, vaginal or vulval cancer.

B. Anticipated Benefits

Follow-up which concentrates on identifying and dealing with problems associated with gynaecological cancers and their treatment is likely to improve women's quality of life. Reducing routine follow-up and investigation for asymptomatic women who have had curative treatment for endometrial cancer could reduce costs.

C. Evidence

There is no reliable evidence that shows what, if any, form of routine follow-up may be appropriate for women who have completed treatment for gynaecological cancers, nor is there consensus on what might be appropriate. These women may suffer from a variety of problems for which interventions are available (see Topic 2, *The Patient's Perspective*). A small pilot study found that 81% of women reported to be free of disease experienced psychosocial difficulties after treatment for gynaecological cancer.(B) About half of women report problems with physical adverse effects of treatment.(B) In the second year after treatment for ovarian cancer (predominantly stage III), 34% of women who appeared to be free of disease reported continued impairment of physical activity and 47% had not returned to their pre-treatment level of sexual activity.(B)

There is no research evidence showing that routine follow-up improves outcomes for asymptomatic women whose cancer appears to have been completely removed. A UK survey found that 85% of 684 gynaecologists followed up their patients using

one of 106 different protocols. Reasons given for follow-up included reassurance for patients, to collect data on outcome, to monitor effects of treatment, habit, and medico-legal concerns.(C)

In endometrial cancer, 80% of recurrences occur within three years. In 60-80% of cases, recurrence causes symptoms (usually vaginal bleeding or pain) and is likely to be reported by the patient to her GP.(B) Retrospective studies from Scotland and Canada suggest that routine out-patient follow-up after curative treatment of endometrial cancer does not improve survival.(B)

Pap smears from the vaginal vault are unhelpful for detection of recurrent endometrial cancer, and have poor (13%) sensitivity for the detection of recurrent cervical cancer.(B) Clinical examination can sometimes lead to earlier detection of recurrent cervical cancer, but it is not clear whether this is associated with improved outcomes. Effective treatment is possible for a minority of women with locally recurrent endometrial or cervical cancer and long-term survival can sometimes be achieved (see Topic 6, *Endometrial Cancer: Treatment* and Topic 8, *Cervical and Vaginal Cancers: Treatment*).

Recurrent ovarian cancer can develop at any time after initial treatment. There is no evidence on optimum follow-up intervals or on the nature of such surveillance, but the involvement of specialist multidisciplinary teams appears to improve survival.(B)

D. Measurement

Structure

- A documented policy on follow-up for each type of gynaecological cancer, drawn up jointly by Cancer Centres and associated Cancer Units.

Process

- Availability of psychosocial interventions such as counselling for women who have been treated for gynaecological cancer.
- Clear access for patients to specialist help with specific adverse effects of treatment, including lymphoedema and bladder or bowel problems.

Outcome

- Morbidity after treatment.
- Audit of rates of detection of asymptomatic recurrence in routine follow-up and subsequent morbidity/mortality.
- 5-year survival rates after treatment for recurrence.

E. Resource Implications

- Reducing routine follow-up for women who have had curative treatment for gynaecological cancers is likely to reduce hospital costs.

Palliative Treatment and Care

Women with advanced gynaecological cancers may benefit both from treatment of the cancer (see Topic 4, *Ovarian Cancer: Treatment*; Topic 6, *Endometrial Cancer: Treatment*; Topic 8, *Cervical and Vaginal Cancers: Treatment*; Topic 9, *Vulval Cancer*) and from palliative care. These are overlapping approaches to management; palliative care should not be seen as an alternative to other interventions.

A. Recommendations

The aim of palliative care is to improve quality of life and the whole person should always be considered. Throughout the course of the illness, provision should be made both for symptom control and to maintain the social and psychological well-being of patients and their carers (see Topic 2, *The Patient's Perspective*). Particular attention should be given to adequate pain control, for which effective interventions should be readily available.

A variety of interventions may be appropriate, ranging from further radical treatment or palliative surgery (for example, to relieve bowel obstruction and problems associated with fistulae) to radiotherapy or medical treatment. Patients should be given realistic information about potential benefits, limitations and adverse effects of interventions and their views should be respected.

Delivery of Services

Most women with advancing cancer are likely to wish to remain at home for much of the duration of their illness, under the care of general practitioners. Multiprofessional palliative care teams should also be involved (see Topic 1, *Specialist Services and Multiprofessional Teams*). These teams should aim to provide both optimal relief from symptoms and social and psychological support for patients and their carers. They should, at a minimum, include a specialist in palliative medicine, a specialist palliative care nurse and social worker support; they should meet regularly and liaise closely with primary care teams.

The main role of the palliative care specialist is likely to be in the provision of education and advice for other health professionals, but he or she may take on the role of lead clinician and have overall responsibility for the management of care for the patient.

When palliative surgery, chemotherapy, or other specialist procedures may be appropriate for symptom control, the palliative care specialist should discuss management options with the specialist gynaecological oncology team at the Cancer Centre. Interventions may be delivered at Cancer Centres or Cancer Units, depending on the type and degree of expertise required, and the patient's condition

and preferences. Local arrangements should be jointly agreed by Cancer Centres and Cancer Units. Efficient systems to ensure rapid and effective communication between each of these levels and teams are essential.

The palliative care team should have access to other skills including counselling for patients with advanced incurable illness, spiritual guidance, dietary advice, and practical support. All health care professionals who deal with these patients should be encouraged to take training in communication and in understanding the needs of women with incurable illness.

All women with advanced disease, whether in hospital or in the community, should have access to specialist palliative care on a 24-hour basis and there should be local arrangements to ensure continuity of care. Patients should be helped to remain in the place they prefer, whether this is their home, hospital, or hospice, and should, whenever possible, be allowed to choose where they wish to die.

B. Anticipated Benefits

Provision of effective palliative treatments and adequate pain control, combined with high quality care services, can improve quality of life for women with advanced gynaecological cancer. Effective palliative care by community-based teams allows patients to stay at home longer; this is preferred by most patients.

C. Evidence

About a quarter of women with late stage ovarian cancer suffer from bowel obstruction; median survival in this group is around 14 weeks. Chronic intestinal obstruction causes pain, nausea, vomiting, constipation and bleeding; it is usually managed by medical and dietary means, but palliative surgery may be beneficial. Surgery to relieve obstruction appears to offer about two months palliation, but there is no research information on the effects of surgery on quality of life.(B)

Fistulae and/or impaired bladder or bowel function can result from cancer or treatment and the patient's quality of life may be improved by palliative surgery.(C)

Over 40% of women with ovarian cancer suffer pain and for more than half of this group, the pain is so severe that it interferes substantially with function.(B) 50% of patients experience physical distress that lasts two years or more, and 33% suffer high levels of psychological distress.(B) Other types of advanced gynaecological cancers can also cause severe pain. Cancer pain is often poorly controlled; the severity of pain experienced by patients may not be recognised and appropriate drugs are under-used.(B) Cancer pain generally can be well controlled in 75-85% of patients treated according to World Health Organisation recommendations.(A)

A specialist multiprofessional palliative care team which meets regularly can offer a higher quality service than conventional care.(A) Referral to specialist palliative care services leads to improvements in pain control and reductions in the severity of other symptoms.(B) There is evidence for the value of specialist nurses in the palliative care team.(B) Home care can achieve good outcomes when team members meet regularly and visit patients at home.(A) Studies in Italy and the US suggest that home care may be less expensive than hospital in-patient care.(B)

D. Measurement

Structure

- A documented clinical policy to guide symptom assessment and treatment.
- Evidence that adequately resourced and staffed palliative care services are available for all patients.
- Evidence that specialist pain relief services are available when required.
- Providers should demonstrate clear mechanisms for referral to, and communication between, primary care, community, Cancer Unit and Cancer Centre teams involved in the delivery of palliative treatment and care.

Process

- The proportion of patients referred to specialist palliative care services should be audited.
- Documentation showing what care is actually provided, and by whom.

Outcome

- Audit of access to, and timeliness of referral to, the palliative care team.
- Results of symptom control audits.
- Surveys of satisfaction with care.

E. Resource Implications

- Palliative treatment of women with advanced disease accounts for a considerable proportion of the total cost of managing gynaecological cancer.
- Increased resources will be required in some areas to create effective multiprofessional palliative care teams and to monitor outcomes.
- Care at home, managed by suitably resourced teams, can cost less than hospice or hospital care.

Appendix 1

Developing the Guidance: the Process

A1

The methodology used for the production of this guidance document is the same as that developed for the production of the earlier guidance documents (on breast, colorectal and lung cancers). Both the process and the identities of those involved (lists in appendix 2), need to be open to scrutiny. The methodology, which was developed specifically for this work, is summarised in the figure which identifies the four main stages. The process is sequential, with each of the first three stages contributing a body of material from which the final document is then drawn. A particular feature is the openness of the process to external views allowing proposals to be challenged and fresh evidence introduced.

The initial stage is a residential event at which people from a range of disciplines and organisations identify what they believe to be the most important attributes of a cancer service necessary to deliver good outcomes. These are set out in a common format and constitute a set of proposals. Each proposal includes key elements such as the evidence on which it is based, implications for the NHS, and relationships to outcome.

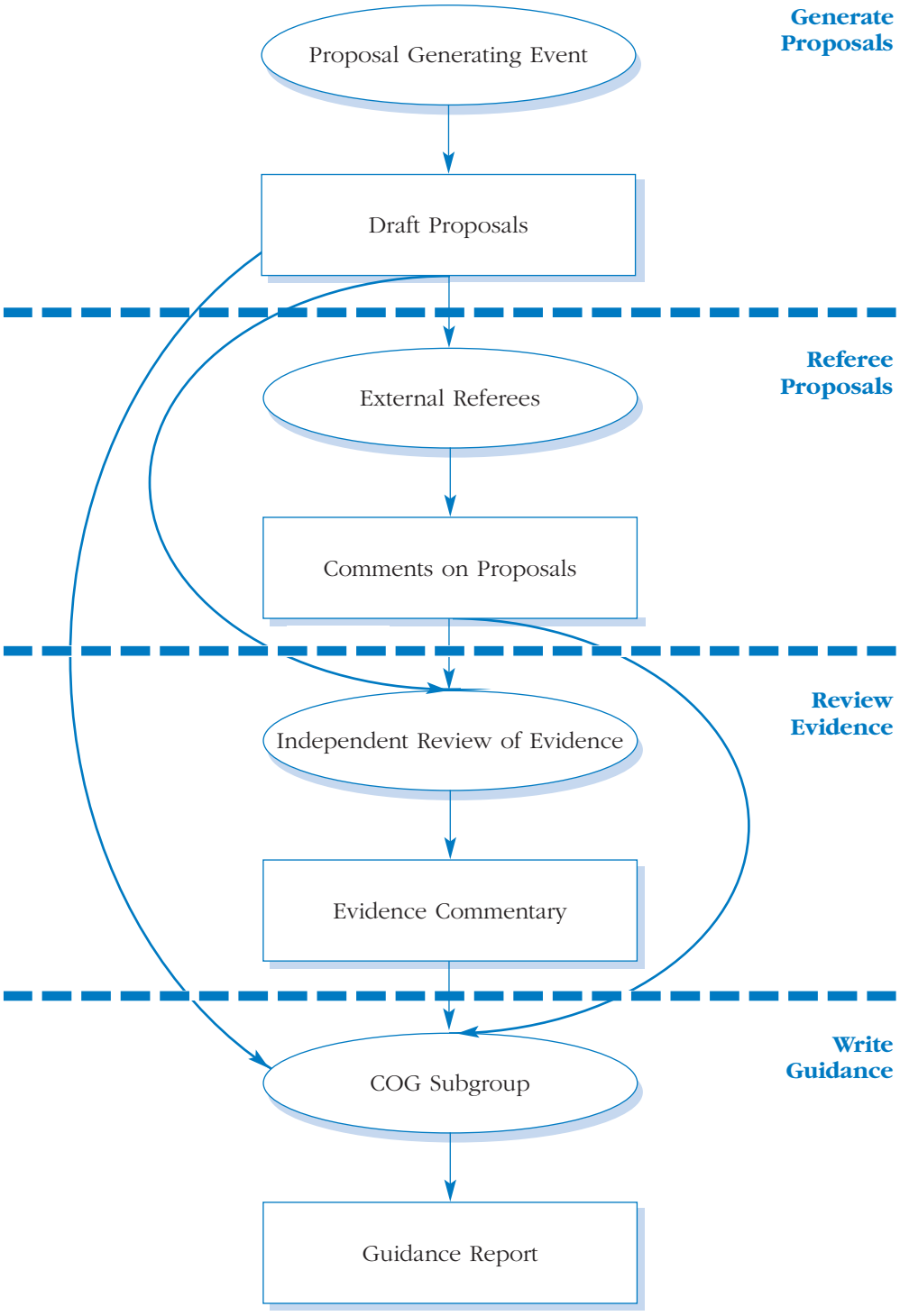
These proposals are then subject to refereeing, involving a spectrum of clinical opinion, those likely to use the eventual guidance, and organisations representing the concerns of cancer patients. The comments of referees are collated for use in committee, but the full comments, together with the original proposals, go into the evidence review stage.

Evidence reviews are commissioned through the NHS Centre for Reviews and Dissemination at the University of York and separately funded by the Research and Development Directorate. The task of the reviewers is to prepare a systematic assessment of the nature and strength of the evidence underlying the proposals and arising from comments by referees. This work is summarised in the *Research Evidence* which supports this manual.

The synthesis of the three strands of work into a coherent report is overseen by the National Cancer Guidance Steering Group (which has replaced the Cancer Guidance Group), most of whose members are not involved in the earlier stages of any one site-specific report. The shaping of the document is assisted by feedback from Commissioners on issues of style and content.

Cancer Guidance Methodology

What did we do?



Appendix 2

People and Organisations Involved in Production of the Guidance

A2

2.1. National Cancer Guidance Steering Group/Cancer Guidance Group

2.2 Members of the proposal generating group

2.3 People/organisations invited to comment on original proposals

2.4 Researchers carrying out literature and economic reviews

2.5 Members of commissioners focus groups

Guidance synthesis and writing

Dr A Melville, Research Fellow
Ms A Eastwood, Senior Research Fellow
Professor J Kleijnen, Director
NHS Centre for Reviews and Dissemination, University of York

assisted by members of the National Cancer Guidance Steering Group, together with:

Dr H M Earl, Senior Lecturer and Honorary Consultant in Medical Oncology, Addenbrooke's Hospital, Cambridge
Dr M E Gore, Consultant Cancer Physician, The Royal Marsden Hospital, London
Dr R D Hunter, Director of Clinical Oncology, Christie Hospital, Manchester
Professor H C Kitchener, Professor of Gynaecological Oncology, St Mary's Hospital for Women and Children, Manchester
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People/organisations invited to comment on drafts of the guidance
National Cancer Guidance Steering Group
Commissioner Focus Groups
Various professional organisations
Department of Health

Economic Reviews
School of Health and Related Research, University of Sheffield

Project support
The Northern and Yorkshire Cancer Registry and Information Service

Appendix 2.1

Membership of the National Cancer Guidance Steering Group

A2.1

Note: The original Cancer Guidance Group set up to oversee the development and production of the first guidance documents was superseded by a smaller National Cancer Guidance Steering Group in November 1998. The membership of the new and original Groups is given below. The continued interest and involvement of members from the wider Group is gratefully acknowledged.

Chairman

Professor R A Haward	Professor of Cancer Studies, University of Leeds

Vice Chairman

Professor M Richards	Sainsbury Professor of Palliative Medicine, St Thomas's Hospital, London

Members

Dr J Barrett	Consultant Clinical Oncologist, Royal Berkshire Hospital
Ms A Eastwood	Senior Research Fellow, NHS Centre for Reviews & Dissemination, York
Dr A Hibble	GP, NHS Executive - Eastern
Professor R Mansel	Chair, Royal College of Surgeons working group on Guidelines for Cancer
Ms T Norman	Cancer Strategy Co-ordinator, Department of Health, Wellington House
Dame G Oliver	Director of Patient Services, Clatterbridge Centre for Oncology
Mrs V Saunders	Manager, Northern and Yorkshire Cancer Registry and Information Service
Dr J Verne	Consultant in Public Health Medicine, NHS Executive - London

Membership of the Cancer Guidance Group

Chairman

Professor R A Haward	Professor of Cancer Studies, University of Leeds

Vice Chairman

Professor M Richards	Sainsbury Professor of Palliative Medicine, St Thomas's Hospital, London

Members

Dr S Atkinson	Regional Director of Public Health, NHS Executive - London
Dr J Austoker	Director of Cancer Research Campaign Primary Care Education Group, University of Oxford
Professor C C Bailey	Regional Director of R&D, NHS Executive - Northern & Yorkshire
Dr J Barrett	Consultant Clinical Oncologist, Royal Berkshire Hospital
Mr M Bellamy	Chief Executive, Ealing, Hammersmith and Hounslow Health Authority
Professor J Carmichael	CRC Professor of Clinical Oncology, Nottingham City Hospital
Professor J Hardcastle	Chair, Royal College of Surgeons Cancer Committee
Mrs S Hawkett	Nursing Officer, Department of Health, Wellington House
Professor J Kleijnen	Director, NHS Centre for Reviews & Dissemination, University of York
Dr A Kostick	GP, Aylesbury
Ms J McKessack	Assistant Secretary, Department of Health, Wellington House
Professor R Mansel	Chair, Royal College of Surgeons working group on Guidelines for Cancer
Mrs R Miles	Regional Cancer Adviser, NHS Executive - West Midlands; Chairman of National Cancer Alliance
Dame G Oliver	Director of Patient Services Clatterbridge Centre for Oncology
Professor P Quirke	Reader in Pathology, University of Leeds
Professor I Williams	Professor of General Practice, University of Nottingham
Dr E Wilson	Senior Medical Officer, Department of Health, Wellington House

Appendix 2.2

Participants in the Gynaecological Cancers Proposal Generating Event

A2.2

Ms V Allanach	Adviser to the Royal College of Nursing
Dr C M Anderson	GP, Stockport
Dr J M Barrett	Consultant Clinical Oncologist, Royal Berkshire Hospital
Mr D P J Barton	Consultant Gynaecological Oncologist, The Royal Marsden Hospital, London
Dr P Blake	Consultant Clinical Oncologist, The Royal Marsden Hospital, London
Mrs V Brennan	Patient, West Yorkshire
Mr J Buxton	Consultant Gynaecological Surgeon/Oncologist, The General Infirmary at Leeds
Dr S Chan	Consultant Clinical Oncologist, Nottingham City Hospital
Dr E A Charlesworth	Consultant in Public Health Medicine, North Derbyshire Health Authority
Mr P K Clarkson	Consultant Obstetrician and Gynaecologist, Mayday University Hospital, Surrey
Dr H M Earl	Senior Lecturer and Honorary Consultant in Medical Oncology, Addenbrooke's Hospital, Cambridge
Dr T S Ganesan	Consultant Medical Oncologist, The Churchill Hospital, Oxford
Dr M E Gore	Consultant Cancer Physician, The Royal Marsden Hospital, London
Dr J Halpin	Consultant/Senior Lecturer in Public Health Medicine, East and North Hertfordshire Health Authority
Mr G Harris	Consultant Obstetrician and Gynaecologist, Lewisham Hospital, London
Dr A Herbert	Consultant Histo/cytopathologist, Southampton General Hospital
Dr D Hole	Deputy Director, West of Scotland Cancer Surveillance Unit, Ruchill Hospital, Glasgow
Mrs C Holmes	Patient, West Yorkshire
Dr R D Hunter	Director of Clinical Oncology, Christie Hospital, Manchester
Ms S Hunton	Director, Bradford Cancer Support Centre
Professor J Husband	Professor of Radiology, The Royal Marsden Hospital, Surrey
Dr E Junor	Consultant Clinical Oncologist, Beatson Oncology Centre, Glasgow
Dr S Kelly	GP, Chichester

Professor H C Kitchener	Professor of Gynaecological Oncology, St Mary's Hospital for Women and Children, Manchester
Dr R Lane	Lead Clinician for Cancer Services, Dewsbury Health Care
Mrs J Lloyd Bartle	Patient, West Yorkshire
Dr E McGoogan	Clinical Director of Pathology, The University of Edinburgh Medical School
Mrs N Martin	Diagnostic Radiographer, Hammersmith Hospital, London
Dr A Melville	Writer, NHS Centre for Reviews and Dissemination, York
Mr J M Monaghan	Director of Gynaecological Oncology Services, Queen Elizabeth Hospital, Gateshead
Mrs M Oglesby	Patient, West Yorkshire
Dr T J Perren	Senior Lecturer and Consultant Cancer Physician, St James's University Hospital, Leeds
Dr F A Pitt	Consultant in Public Health Medicine, Sheffield Health Authority
Mrs N Preston	Nurse Research Practitioner, Centre for Cancer and Palliative Care Studies, The Royal Marsden Hospital, London
Mrs J Riches	Oncology Directorate Service Manager, Norfolk and Norwich Hospital
Mr J H Shepherd	Consultant Gynaecological Surgeon and Oncologist, St Bartholomew's Hospital, London
Ms K Steele	Macmillan Nurse, Rotherham District General Hospital
Dr H Thomas	Consultant Clinical Oncologist, Hammersmith Hospital, London
Dr J Thomas	Director of Public Health, Sunderland Health Authority
Ms L Thomson	Deputy Chief Nursing Officer, Macmillan Cancer Relief
Dr P Watson	Director of Acute Services, Cambridge and Huntingdon Health Authority
Professor M Wells	Professor of Gynaecological Pathology, University of Sheffield Medical School
Dr J Wilkinson	Deputy Director of Public Health, North Yorkshire Health Authority
Dr M P Williams	Consultant Radiologist, Derriford Hospital, Plymouth
Dr C Wolfe	Clinical Director, Women's Services, St Thomas' Hospital, London
Professor C Woodman	Professor of Public Health and Cancer Epidemiology, Christie Hospital, Manchester

Facilitated by:

Professor R A Haward	Professor of Cancer Studies, University of Leeds
Professor M Richards	Sainsbury Professor of Palliative Medicine, St Thomas' Hospital, London

Appendix 2.3

Referees of the Gynaecological Cancers Proposals

A2.3

Invited to comment:

Dr M Adams	Consultant in Clinical Oncology, Velindre Hospital, Cardiff
Professor G Alberti	President, Royal College of Physicians
Mr M Al-Kurdi	Consultant Obstetrician and Gynaecologist, Hinchingbrooke Hospital, Huntingdon
Dr A Al-Nafussi	Senior Lecturer and Honorary Consultant in Pathology, The University of Edinburgh Medical School
Ms V Allanach	Adviser to the Royal College of Nursing
Dr C M Anderson	GP, Stockport
Dr M C Anderson	Reader in Gynaecological Pathology, Queen's Medical Centre, Nottingham
Mr R S Anderson	Consultant Obstetrician and Gynaecologist, St Michael's Hospital, Bristol
Mr R W Anderson	Economic Adviser, Department of Health
Dr D P M Archer	GP, Hemel Hempstead
Dr M Armstrong	GP, Stockport
Dr D V Ash	Dean, Faculty of Clinical Oncology, The Royal College of Radiologists
Professor M R Baker	Medical Director, North Yorkshire Health Authority
Mrs D Barker	Macmillan Nurse Consultant, The Macmillan Education Centre, Harrogate
Dr V L Barley	Consultant Clinical Oncologist, Bristol Oncology Centre
Professor D H Barlow	Nuffield Professor of Obstetrics and Gynaecology, John Radcliffe Hospital, Oxford
Mr D P J Barton	Consultant Gynaecological Oncologist, The Royal Marsden Hospital, London
Dr J Bell	Consultant in Public Health Medicine, North Staffordshire Health Authority
Mr M Bellamy	Chief Executive, Ealing, Hammersmith and Hounslow Health Authority
Professor A J Bellingham	President, The Royal College of Pathologists
Mr G Bennett	Director of Finance, Birmingham Health Authority
Dr P Bevan	Director of Public Health, Merton, Sutton and Wandsworth Health Authority
Dr P Blake	Consultant Clinical Oncologist, The Royal Marsden Hospital, London
Dr P Bridger	Consultant in Public Health Medicine, East Sussex, Brighton and Hove Health Authority
Dr S Bridgman	Consultant in Public Health Medicine, North Staffordshire Health Authority

Dr M J Brindle	President, The Royal College of Radiologists
Dr C H Buckley	Reader in Gynaecological Pathology, St Mary's Hospital for Women and Children, Manchester
Mrs M Bullen	Macmillan Nurse Consultant, South West Southern Region
Dr J Bullimore	Member of the National Cancer Forum
Mr J Buxton	Consultant Gynaecological Surgeon/Oncologist, The General Infirmary at Leeds
Professor Sir K C Calman	Vice Chancellor, University of Durham
Professor A H Calvert	Professor of Clinical Oncology, Newcastle General Hospital, Newcastle-upon-Tyne
Mr D Campbell	Director of Finance, Liverpool Health Authority
Ms S Campbell	Research Nurse, Western General Hospital, Edinburgh
Professor S Campbell	Professor of Obstetrics and Gynaecology, St George's Hospital, London
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Mr K K Chan	Consultant Gynaecological Surgeon and Gynaecological Oncologist, Birmingham Women's Hospital
Dr S Chan	Consultant Clinical Oncologist, Nottingham City Hospital
Dr E A Charlesworth	Consultant in Public Health Medicine, North Derbyshire Health Authority
Dr C D A Charlton	Consultant Clinical Oncologist, Royal Berkshire Hospital
Mr F M L Charnock	Consultant Obstetrician and Gynaecologist, John Radcliffe Hospital, Oxford
Dr J Chesworth	Associate Director, GP Services, North Staffordshire Health Authority
Mr P K Clarkson	Consultant Obstetrician and Gynaecologist, Mayday University Hospital, Surrey
Dr A Clover	Consultant Homeopathic Physician, Royal London Homeopathic Hospital
Dr R E Coleman	Reader in Medical Oncology, Weston Park Hospital, Sheffield
Ms P Cook	Assistant Chief Executive, NHS Executive - North West
Professor J Corner	Director and Deputy Dean (Nursing), The Centre for Cancer and Palliative Care Studies, The Royal Marsden Hospital, London
Dr B Cottier	Regional Cancer Co-ordinator, NHS Executive - North West
Ms D Crowther	Chief Executive, Wirral Holistic Care Services
Mr J G R Cumming	Member of the National Cancer Forum
Dr R Daniels	Medical Director, The Cancer Help Centre, Bristol
Dr T W Davies	Member of the National Cancer Forum
Ms T Dawson	Macmillan Nurse, Clinical Specialist in Gynaecology, Poole/Dorset area
Dr S J Daye	Commissioning Manager, Complex Health Programme, Ealing, Hammersmith and Hounslow Health Authority
Ms S Dennison	Macmillan Cancer Nurse Specialist, Freedom Fields Hospital, Plymouth
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Dr I Duncan	Consultant Obstetrician and Gynaecologist, Ninewells Hospital and Medical School, Dundee
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Ms K Easton	Advanced Nurse Practitioner, Gloucester Royal Hospital
Mr D Eustace	Lead Clinician for Gynaecological Oncology, Wycombe Hospital, High Wycombe
Mr A Evans	Consultant Gynaecologist, University Hospital of Wales, Cardiff
Mr S Evans	General Secretary and Chief Executive, The College of Radiographers
Professor A Faulkner	Professor of Communication in Health Care, Trent Palliative Care Centre
Mrs K Fell	Therapeutic Radiographer, Nottingham City Hospital
Professor I G Finlay	Professor of Palliative Medicine, Holme Tower Marie Curie Centre, Penarth
Mr A N J Fish	Consultant Obstetrician & Gynaecologist, The Royal Sussex County Hospital
Dr S Ford	GP, Mapperley, Nottingham
Professor H Fox	Professor of Reproductive Pathology, University of Manchester Medical School
Dr T S Ganesan	Consultant Medical Oncologist, The Churchill Hospital, Oxford
Dr R Garlick	Consultant in Public Health Medicine, East London and the City Health Authority
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Dr J D Graham	Consultant Clinical Oncologist, Bristol Oncology Centre
Dr W Gray	Consultant Cyto/Histopathologist, John Radcliffe Hospital, Oxford
Dr J A Green	Senior Lecturer in Medical Oncology and Honorary Consultant Physician, Clatterbridge Centre for Oncology
Lady S Greengross	Director General, Age Concern
Ms C Gritzner	General Manager, The Patient's Association
Dr D Guthrie	Consultant in Clinical Oncology, Derbyshire Royal Infirmary
Dr J Hanson	Cancer Services Project Co-ordinator, Welsh Office
Professor J Hardcastle	Professor of Surgery, University Hospital, Nottingham
Dr M Harding	Senior Registrar in Public Health Medicine, St George's Hospital Medical School, London
Ms R Hamer	Nurse Counsellor, St Bartholomew's Hospital, London
Dr P G Harper	Consultant Medical Oncologist, Guy's Hospital, London
Mr G Harris	Consultant Obstetrician and Gynaecologist, Lewisham Hospital, London
Mr T Harris	Director, Association of Community Health Councils for England and Wales

Dr P Harvey	Consultant Clinical Psychologist, Queen Elizabeth Hospital, Birmingham
Ms A Hayes	Director of Counselling, Cancerlink
Dr V Hempsall	Deputy Director of Public Health, Dorset Health Authority
Ms J Henderson	President, The College of Radiographers
Dr C S Herrington	Senior Lecturer and Honorary Consultant Pathologist, Royal Liverpool University Hospital
Dr F Hicks	Executive Committee Member of the Association for Palliative Medicine, St James's University Hospital, Leeds
Professor P Hill	Postgraduate Dean (Northern), University of Newcastle upon Tyne
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Dr J V Jolleys	Honorary Lecturer in General Practice, University of Nottingham
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Mr R E Kingston	Consultant Obstetrician and Gynaecologist, Liverpool Women's Hospital
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Mr F Lawton	Consultant Gynaecologist, Kings College Hospital, London
Mr S C Leeson	Consultant Obstetrician and Gynaecologist, Ysbyty Gwynedd, Bangor

Mr A Lesseps	Consultant Obstetrician and Gynaecologist, Gravesend and North Kent Hospital
Professor D M Leusley	Professor of Gynaecological Oncology, Birmingham City Hospital
Mr G J Lewis	Consultant Obstetrician and Gynaecologist, Wordsley Hospital, Stourbridge
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Professor RNM MacSween	President, The Royal College of Pathologists
Mr N McWhinney	Consultant Obstetrician and Gynaecologist, St Helier Hospital, Surrey
Dr G P Maguire	Honorary Consultant Psychiatrist, Christie CRC Research Centre, Manchester
Dr J Maher	Consultant Clinical Oncologist, Mount Vernon Hospital, Middlesex
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Dr H Marsh	GP, Cardiff
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Ms K Maughan	Macmillan Nurse and Regional Research Fellow, Queen Elizabeth Hospital, Gateshead
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Ms T Norman	Cancer Strategy Co-ordinator, Department of Health
Dr K O'Byrne	Senior Lecturer and Consultant in Oncology, Leicester Royal Infirmary
Mrs M Oglesby	Patient, West Yorkshire
Dame G Oliver	Director of Patient Services, Clatterbridge Centre for Oncology

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Professor A J Ramirez	Professor of General Hospital Psychiatry, Guy's Hospital, London
Dr A J Rathmell	Consultant Clinical Oncologist, South Cleveland Hospital, Middlesbrough
Mr C W E Redman	Consultant Obstetrician and Gynaecologist, North Staffordshire Hospital, Stoke-on-Trent
Mrs J Reynolds	Project Manager, Policy Support, Dorset Health Authority
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Dr C M Ridley	Senior Lecturer and Honorary Consultant Dermatologist, St Thomas' Hospital, London
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Ms M Rigge	Director, College of Health, London
Mr A A Robertson	Consultant Obstetrician and Gynaecologist, Hartlepool General Hospital
Dr R S Robertson	Consultant Radiologist, Royal Berkshire Hospital
Dr T P Rollason	Consultant Histopathologist, Birmingham Women's Hospital
Mr R I Rothwell	Consultant in Clinical Oncology, Cookridge Hospital, Leeds
Dr G Rustin	Consultant Medical Oncologist, Mount Vernon Hospital, Middlesex
Dr I Rutter	GP, Shipley, West Yorkshire

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Mr C Smee	Chief Economic Adviser, Department of Health
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Dr M F Spittle	Consultant Clinical Oncologist, The Middlesex Hospital, London
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Ms K Steele	Macmillan Nurse, Rotherham District General Hospital
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Ms K Summerville	Clinical Nurse Specialist, The Royal Marsden Hospital, London
Dr R P Symonds	Consultant Clinical Oncologist, Western Infirmary, Glasgow
Dr T Tate	Consultant in Palliative Medicine, The Margaret Centre, Whipps Cross Hospital
Dr H Thomas	Consultant Clinical Oncologist, Hammersmith Hospital, London
Mrs F Thompson	Macmillan Nurse Consultant, South West Southern Region
Mrs H Thornton	Chairman, Consumers' Advisory Group for Clinical Trials
Dr L Turnbull	Consultant Cytologist, Royal Liverpool University Hospital
Dr G Turner	Associate Specialist in Clinical Genetics, St James's University Hospital, Leeds
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Professor M Wells	Professor of Gynaecological Pathology, The University of Sheffield Medical School
Rev Dr M J Whipp	Consultant Clinical Oncologist, Weston Park Hospital, Sheffield
Professor G H Whitehouse	Professor of Diagnostic Radiology, University of Liverpool
Dr M J Whitfield	Consultant Senior Lecturer in General Practice, University of Bristol

Dr J Wight	Consultant in Public Health Medicine, Wakefield Health Authority
Dr S Will	Consultant in Public Health Medicine, Bury and Rochdale Health Authority
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Dr H Winter	Senior Lecturer in Public Health Medicine, University of Birmingham
Dr C Wolfe	Clinical Director, Women's Services, St Thomas' Hospital, London
Professor C Woodman	Professor of Public Health and Cancer Epidemiology, Christie Hospital, Manchester
Dr R W Worth	Consultant Gynaecologist and Obstetrician, Epsom General Hospital
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Ms J Young	Manager and Head of Counselling, Lynda Jackson Macmillan Centre for Cancer Support and Information, Mount Vernon Hospital, Middlesex
Ms T Younger	Regional Cancer Co-ordinator, NHS Executive - London

Department of Health/NHS Executive representatives

224 people were asked to act as referees, of whom 35% responded.

Appendix 2.4

Researchers carrying out literature reviews

Overall Co-ordinators

Ms A Eastwood, Professor J Kleijnen and Dr A Melville — NHS Centre for Reviews and Dissemination, University of York

i) Literature Reviews

Professor H C Kitchener, Dr P Martin-Hirsch and Ms L Nelson — Department of Obstetrics and Gynaecology, St Mary's Hospital for Women and Children, Manchester

contributed reviews which were used to inform guidance on all Topics.

Professor I Higginson and Mr G Sen-Gupta — Department of Palliative Care and Policy, King's College School of Medicine and Dentistry, London

contributed reviews which were used to inform guidance on Topics 1, 2 and 11.

ii) Economic Reviews

Mr A Brennan, Ms F Sampson — School of Health and Related Research, University of Sheffield

A2.4

Appendix 2.5

Focus Groups: Commissioner Membership

Professor M Baker	Medical Director, North Yorkshire Health Authority
Mr M Bellamy	Chief Executive, Ealing, Hammersmith and Hounslow Health Authority
Mr G Bennett	Director of Finance, Birmingham Health Authority *Served on the Group until September 1998*
Dr P Bevan	Director of Public Health, Merton, Sutton and Wandsworth Health Authority
Mr D Campbell	Director of Finance, Liverpool Health Authority
Dr A Charlesworth	Consultant in Public Health Medicine, North Derbyshire Health Authority
Dr J Halpin	Consultant in Public Health, Gateshead & South Tyneside Health Authority
Dr V Hempsall	Deputy Director of Public Health, Dorset Health Authority
Mr J Henly	Director of Health Care Commissioning, Portsmouth and South East Hampshire Health Authority
Dr S Munday	Deputy Director of Public Health, Birmingham Health Authority *Became a member in December 1998*
Dr S Pearson	Director of Public Health, Gloucestershire Health Authority
Dr F Pitt	Consultant in Public Health Medicine, Sheffield Health Authority
Mr R Priestley	Chief Executive, North Staffordshire Health Authority
Dr J Spiby	Director of Public Health, Bromley Health Authority
Dr J Thomas	Director of Public Health, Sunderland Health Authority
Dr J Verne	Consultant in Public Health Medicine, Barnet Health Authority
Dr P Watson	Director of Acute Services, Cambridge and Huntingdon Health Authority
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Facilitated by:

Ms S O'Toole	Consultant in Health Policy and Management

Supported by:

Mrs V Saunders	Manager, Northern and Yorkshire Cancer Registry and Information Service

Appendix 3
Glossary of Terms

Adenocarcinoma
A malignant growth of glandular tissue, adenocarcinoma can develop in any gynaecological organ. Cervical adenocarcinomas are not reliably detected by screening because they may not develop on the surface of the cervix from which smears are taken.

Adjuvant treatment
Treatment used in addition to main treatment, usually *radiotherapy* or *chemotherapy* given after surgery.

Adnexal mass
Mass of tissue on or in a structure associated with the uterus such as an ovary, fallopian tube, or uterine ligament.

Ascites
An accumulation of fluid in the abdominal (peritoneal) cavity.

Atrophy
Wasting of tissue due to lack of use, disease, injury, ageing, or other causes.

Audit
A method by which those involved in providing services assess the quality of care. Results of a process or intervention are assessed, compared with a pre-existing standard, changed where necessary, then reassessed.

Biopsy
Removal of a sample of tissue or cells from the body to assist in diagnosis of a disease.

Brachytherapy
Radiotherapy delivered within an organ. In *vault* brachytherapy, radiotherapy is given inside the vagina, whilst in intracavity brachytherapy, radiotherapy is delivered inside the uterus.

Carcinoma
A cancerous growth.

CA125
A substance which may be found in the blood of women who have ovarian cancer, used as a biochemical marker for the disease.

Cervical intraepithelial neoplasia (CIN)
Altered cells in the surface of the cervix which may be capable of progressing to cancer.

Chemotherapy
The use of drugs that kill cancer cells, or prevent or slow their growth.

Chronic intestinal obstruction
Obstruction of the bowel which can result from cancer in the abdomen. The bowel becomes gradually narrower and may close altogether so that food cannot pass through it; this causes nausea, vomiting, anorexia, constipation, swelling and pain.

Clinical Oncologist
A doctor who specialises in the treatment of cancer patients, particularly through the use of *radiotherapy,* but who may also use *chemotherapy*.

Cognitive and behavioural interventions
Types of therapy, often delivered by psychologists, usually based on talking and practising specific types of voluntary activity. This group of interventions can include, for example, relaxation training, counselling, and psychological approaches to pain control.

Colposcopy
A method of examining the vagina and cervix. Colposcopy involves the use of a colposcope, an instrument which gives a clear view inside the vagina.

Combination Chemotherapy
The use of more than one drug to kill cancer cells.

Computed Tomography (CT)
Computed tomography, an X-ray imaging technique.

Condylomata
Localised swellings around the genital organs caused by infection, sometimes known as genital warts.

Cone (loop) biopsy
Removal of a cone-shaped section of tissue from the centre of the cervix for pathological assessment.

Curative Resection
An operation in which the surgeon believes that all cancer-containing tissue has been removed.

Cytology
The study of the appearance of individual cells under a microscope.

Cytopathologist
A person who specialises in diagnosis through detecting and identifying disease in individual cells.

Cytotoxic
Toxic to cells. This term is used to describe drugs which kill cancer cells or slow their growth.

Debulking
Removal by surgery of a substantial proportion of cancer tissue. Optimal debulking refers to the removal of the largest possible amount of cancer while limiting damage to normal tissue; interval debulking refers to surgical removal of tumour after *chemotherapy* aimed at further reducing its bulk.

Differentiation
The degree of morphological resemblance between cancer tissue and the tissue from which the cancer developed.

Dilatation and curettage (D&C)
Opening the cervix with a series of dilators and scraping the lining of the uterus. This procedure normally requires a general anaesthetic.

Endometrium
The lining of the uterus.

Exenterative surgery
Removal of the pelvic organs including the uterus, ovaries and associated organs and the bladder and/or large bowel.

FIGO
International Federation of Gynaecology and Obstetrics. FIGO defines staging in gynaecological cancer and collates information about treatment and survival from a group of collaborating European centres (including some in the UK).

First-degree relative
First-degree female relatives are full sisters, mothers and daughters.

Fistula (plural: fistulae)
A hole in tissue where a hole would not normally exist. In women who have been treated for gynaecological cancer, fistulae can develop, for example, between the vagina and bladder or between the rectum and the vagina.

Gynaecology
The branch of medicine which deals with the female reproductive organs.

Heterogeneous
Of differing origins, or different types.

Histological grade
Degree of malignancy of a tumour, usually judged from its histological features.

Histological type
The type of tissue found in a tumour.

Histology
Examination of the microscopic structure of tissue.

Histopathologist
A person who specialises in the diagnosis of disease through study of the microscopic structure of tissue.

Human papilloma virus (HPV)
A virus that causes genital warts. HPV is the main cause of cervical cancer.

Hyperplasia
Enlargement of an organ, or tissue within it, due to an increase in the number of cells.

Hysterectomy
Surgical removal of the uterus.

Hysteroscopy
Inspection of the inside of the uterus using a special instrument called a hysteroscope.

Inter-menstrual bleeding
Vaginal bleeding between menstrual periods.

Localised disease
Tumour confined to a small part of an organ.

Loop biopsy
See cone biopsy.

Lymph nodes
Small organs which act as filters in the lymphatic system. Lymph nodes close to the primary tumour are often the first sites to which cancer spreads.

Lymphadenectomy
Surgical removal of *lymph nodes*.

Lymphadenopathy
Disease of the *lymph nodes*.

Lymphoedema
Swelling, usually in a limb, caused by an accumulation of lymphatic fluid. This may be a complication of cancer treatment.

Magnetic resonance imaging (MRI)
A non-invasive method of imaging which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance).

Medical Oncologist
A doctor who specialises in the treatment of cancer through the use of *chemotherapy*.

Menopause
The end of menstruation; this usually occurs naturally at around the age of 50.

Meta-analysis
The statistical analysis of the results of a collection of individual studies to synthesise their findings.

Metastases
Spread of cancer away from the primary site.

Morphology
Shape or form.

Myometrial invasion
Spread of cancer into the muscular wall of the uterus.

Neo-adjuvant treatment
Treatment given before the main treatment; usually *chemotherapy* or *radiotherapy* given before surgery.

Nodes
See *Lymph nodes*.

Non-neoplastic
Tissue that does not contain tumour.

Oncologist
A doctor who specialises in treating cancer.

Oncology
The study of the biology and physical and chemical features of cancers. Also the study of the causes and treatment of cancers.

Oophorectomy
Removal of the ovaries.

Palliative
Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it. Hence palliative care, palliative *chemotherapy*.

Pap smears
Cells scraped from the surface of the cervix or vagina for examination under the microscope.

Parametrium
Tissue and structures such as ligaments around the uterus.

Peritoneal washings
Fluid taken from the abdominal (peritoneal) cavity during surgery.

Pipelle aspirator
A device used to draw samples of tissue from the lining of the uterus.

Placebo
Fake or inactive interventions received by participants allocated to control groups in clinical trials, used to allow investigators to quantify any effect of the treatment over and above care and attention.

Polycystic ovary disease
A condition in which one or both ovaries become enlarged and develop non-malignant cysts which may affect hormone balance.

Post-coital
After sexual intercourse.

Post-menopausal vaginal bleeding
Vaginal bleeding a year or more after periods have ceased because of the *menopause.*

Progestogens
Synthetic substances which are chemically similar to the natural hormone, progesterone.

Prophylaxis
An intervention used to prevent an unwanted outcome.

Protocol
A policy or strategy which defines appropriate action.

Psychosexual
Psychological aspects of sexual experience and behaviour.

Psychosocial
Concerned with psychological influences on social behaviour.

Quality of life
The individual's overall appraisal of her situation and subjective sense of well-being.

Radical radiotherapy
Radiotherapy given with curative, rather than *palliative,* intent.

Radiotherapy
The use of radiation, usually X-rays or gamma rays, to kill tumour cells.

Remission
A period when cancer has responded to treatment and there are no signs of tumour or tumour-related symptoms.

Resection
The surgical removal of all or part of an organ.

Sarcoma
Cancer derived from connective tissue; a rare type of gynaecological cancer.

Squamous cell carcinoma
A common type of cancer which originates in superficial layers of tissue (squamous epithelium).

Staging
The allocation of categories (stage I to IV) to tumours defined by internationally agreed criteria. Stage I tumours are localised, whilst stages II to IV refer to increasing degrees of spread through the body from the primary site. Tumour stage is an important determinant of treatment and prognosis.

Superficially invasive cervical disease
Cancer which penetrates the tissue of the cervix to a depth of less than 5mm and a width of less than 7mm; this is associated with a negligible risk of lymph node *metastases* and therefore may be treated conservatively.

Surgical margins
The edges of the tissue removed during surgery.

Total abdominal hysterectomy and bilateral salpingo-oophorectomy (TAH/BS0)
Removal of the uterus with both fallopian tubes and ovaries through an incision in the abdomen.

Transvaginal ultrasound
Imaging of the interior of the pelvis using *ultrasound* delivered by a probe inserted into the vagina.

UKCCCR
United Kingdom Co-ordinating Committee on Cancer Research. The national committee responsible for co-ordinating clinical trials for cancer treatment in the UK.

Ultrasound
High-frequency sound waves used to create images of structures and organs within the body.

Ureters
Tubes which carry urine from the kidneys to the bladder.

Vaginal vault smears
Pap smears taken from the vagina, usually after *hysterectomy*.

Vascular space invasion
Tumour in blood or lymphatic vessels.

Produced by Department of Health
16149 1P 14,550 July 99 (CWP)
CHLORINE FREE PAPER