

Overtain cancer is sometimes described as the silent killer because it rarely gives working eigns. it is the fourth most common cancer affecting women in Scotland. Over 500 cases are diagnosed each year Less than 3070 of nomen since five years after diagnosis.

# Fighting the silent killer

Optimising ovarian cancer management in Scotland

M A R C H 1 9 9 8

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Appendices

The Accounts Commission is a statutory, independent body which, through the audit process, assists the health service and local authorities in Scotland to achieve the highest standards of financial stewardship and the economic, efficient and effective use of their resources.

The Commission has five main responsibilities:

- · securing the statutory external audit
- following up issues of concern identified through the audit to ensure a satisfactory resolution
- reviewing the management arrangements which audited bodies have in place to achieve value for money
- carrying out national value for money studies to improve economy, efficiency and effectiveness in the NHS and local authorities
- issuing an annual direction to local authorities setting out the range of performance information which they have to publish.

The Commission assists the NHS in achieving value for money by highlighting good practice, providing comparative information, and supporting auditors in reviewing performance locally. Its Health and Social Work Studies Directorate is responsible for managing a national programme of value for money studies. Part of the 1996-97 programme included a review of the management of ovarian cancer

#### Acknowledgements

The study was managed by Angela Canning and Sara Twaddle under the general direction of Caroline Gardner, Director of Health and Social Work Studies. The project team received advice and comments from an advisory panel of representatives from the NHS during the development of this review (appendix 1).

The Accounts Commission is grateful to the trusts and health boards which participated in local reviews, and to those trusts which completed questionnaires. We are also grateful to members of the advisory panel and to the other individuals who offered comments on drafts of this report. Thanks go to the Information and Statistics Division for the provision and analysis of data.

Responsibility for the contents and conclusions rests solely with the Accounts Commission.

### Executive summary

Cancer is one of the key priorities for the NHS in Scotland. Cancer of the ovary is the most common gynaecological cancer, with over 500 new cases diagnosed in Scotland each year<sup>1</sup>. An audit of all cases of ovarian cancer registered in Scotland in 1987<sup>2</sup> showed differences in how ovarian cancer was managed, including the organisation of care and surgical treatment<sup>1</sup>. The average five year survival rate for Scotland is amongst the poorest in Europe<sup>3</sup>, and rates have been shown to vary between health boards<sup>4</sup>.

The findings from the audit of cases registered in 1987 led the Scottish Executive of the Royal College of Obstetricians and Gynaecologists to set up a multidisciplinary steering group to produce a guideline on how ovarian cancer should be managed. This guideline was published by the Clinical Resource and Audit Group (CRAG) in 1995<sup>5</sup>. It includes recommendations on referral patterns, surgery, pathological assessment, chemotherapy and post-surgical management.

The Accounts Commission has reviewed the arrangements for the management of ovarian cancer within a sample of trusts and health boards, looking at the processes in place for managing ovarian cancer in line with the CRAG guideline. Local reports have been produced for these sites. A questionnaire was also sent to the other acute trusts and directly managed units in Scotland.

Overall, trusts and health boards are addressing the recommendations raised in the CRAG guideline on the management of ovarian cancer, although the extent to which the recommendations have been adopted varies. Our main findings are summarised below.

- Gynaecology and general surgery departments have been discussing the referral of patients to gynaecologists with a special interest in gynaecological malignancy. However, there are still cases where patients are not routinely referred to a gynaecologist with a special interest.
- Although research has shown that survival improves following post-surgical referral to a multidisciplinary clinic, not all trusts refer ovarian cancer patients to a combined gynaecology oncology clinic.
- Where considered appropriate, eligible patients are treated with platinum-based chemotherapy. However, not all appropriate patients are routinely asked if they would consider entering clinical trials.
- Despite the publication of the CRAG guideline which sets out the recommended practice for managing patients with ovarian cancer, some trusts are not undertaking clinical audit of the management of this disease. Where clinical audit is conducted, findings are not always routinely reported to health boards. This makes it difficult to establish how health boards ensure that patients are receiving treatment in line with recommended practice.
- Communication between hospital staff and ovarian cancer patients is generally good. Patients are provided with information booklets on the disease and its treatment, and offered support once they return home from hospital. However, there is little research in hospitals into the views of ovarian cancer patients or their relatives on the service being provided or their information needs.

<sup>&</sup>lt;sup>1</sup>A further audit is now being undertaken of all women registered with ovarian cancer in 1992, 1993 and 1994 (Scottish Cancer Therapy Network, *Third Annual Report 1995-96*. 1996)

• Health boards and trusts are taking a collaborative approach to the development of cancer services, with hospital clinicians, nurses and GPs among others being involved and consulted in plans for the future provision of services. Groups have also been established which focus particularly on the gynaecological cancers, and the CRAG guideline on the management of cancer of the ovary is being considered and taken forward in this forum.

Although there are many examples of good practice, there is still some way for the NHS in Scotland to go to ensure that patients diagnosed with ovarian cancer receive the treatment outlined in the CRAG guideline. Until this is achieved, some patients will not have access to the best possible treatment.

# 1 Introduction

#### Incidence

Cancer services are one of the key clinical priorities for the NHS in Scotland<sup>6</sup>. Around 28,000 new cases of cancer are diagnosed in Scotland each year; one in three Scots will get cancer and one in four will die from it. Cancer of the ovary is the fourth most common cancer affecting women in this country, and the most common and fatal of the gynaecological cancers (exhibit 1).

	Cancer	Number of registrations	Percentage of all cancers
1	Breast	3058	24.4
2	Lung	1789	14.3
3	Colon & rectum	1655	13.2
4	Ovary	576	4.6
5	Stomach	420	3.4
6	Bladder	417	3.3
7	Uterus	379	3.0
8	Non-Hodgkin's lymphoma	379	3.0
9	Malignant melanoma of skin	369	2.9
10	Cervix	349	2.8
Source: ISD (1996), Scottish Health Statistics 1996			

Exhibit 1: The ten most frequently diagnosed cancers in women, Scotland, 1994

The cause of ovarian cancer is unknown although it is more common in women who have not had children and in older women, with over 80% of cases aged over 50 (exhibit 2 overleaf). It has been described as the 'silent killer': ovarian cancer produces vague symptoms such as abdominal pain and swelling and can go undetected for a long time. Women therefore tend to present at a late stage: over 50% of women with ovarian cancer are diagnosed only after the disease has spread outside the ovary, making successful treatment difficult<sup>7</sup>.

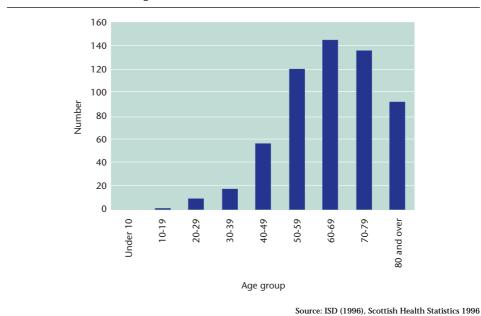
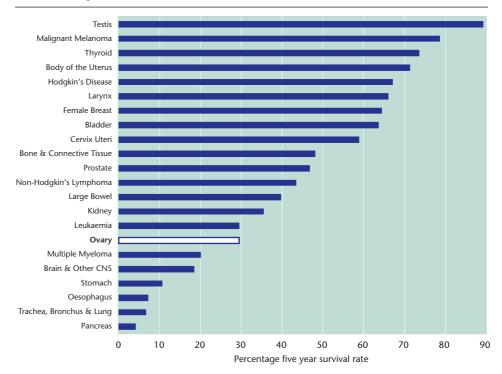


Exhibit 2: Ovarian cancer registrations, 1994

#### Survival

Ovarian cancer has poor prognosis compared with other cancers (exhibit 3) and Scotland has one of the lowest survival rates for ovarian cancer compared with other European countries<sup>8</sup>. Less than 30% of women in Scotland survive five years after diagnosis compared with 38% in Switzerland and 36% in Finland (exhibit 4).

Exhibit 3: Five year relative survival rates, adults, Scotland, 1983-87



Source: Black R J, Sharp L and Kendrick S W (1993), Trends in Cancer Survival in Scotland 1968-1990

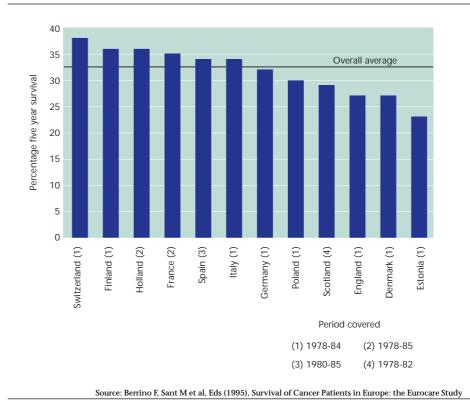


Exhibit 4: Relative five year survival from cancer of the ovary

Five year survival rates for cancer of the ovary have been shown to vary between health boards in Scotland<sup>9</sup> (exhibit 5 overleaf). A cursory look at these comparisons shows that, for example, Grampian Health Board appears to have a far better survival

A number of factors, however, should be taken into account when comparing international and national survival rates. These include method of data collection, type and grade of tumour, age of patients, and random variation. As a result, such comparisons should be treated with a degree of caution.

rate than other health boards.

Health board	Number of registrations at cancer registry in a five year period	Adjusted five year survival rate (%)
Argyll & Clyde	176	19.1
Ayrshire & Arran	177	21.1
Borders	59	29.0
Dumfries & Galloway	62	21.6
Fife	159	20.3
Forth Valley	116	27.7
Grampian	254	42.5
Greater Glasgow	437	25.9
Highland	102	36.4
Lanarkshire	223	27.0
Lothian	373	27.8
Tayside	188	28.5
Scotland <sup>#</sup>	2350	27.8
	Source: CRAG (1	996) Clinical Outcome Indicators 1996

Exhibit 5: Five year survival from ovarian cancer, by health board

#### Implications for the NHS in Scotland

Cancer of the ovary is relatively uncommon, affecting significantly fewer women than breast, lung and colorectal cancers<sup>10</sup> (exhibit 1). However, as well as its high mortality rate, it places significant demands on the NHS in Scotland. During 1995 it was associated with 3,770 hospital episodes, 15,914 inpatient days and 3,790 procedures, of which 680 were major gynaecological or surgical procedures<sup>III</sup>.

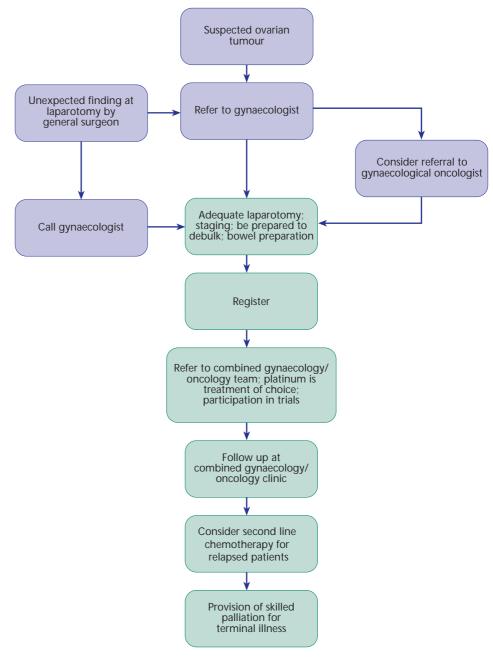
#### **Recommended practice**

Acknowledging the poor survival rates for Scotland, and research showing variations in management of ovarian cancer, the Scottish Executive of the Royal College of Obstetricians and Gynaecologists established a working party to produce guidance on how the disease may best be managed. The working party's guideline was published by CRAG in 1995. The key elements of the guideline are shown in exhibit 6.

 $<sup>{}^{\</sup>scriptscriptstyle I\!\!I}Scotland$  figure includes registrations for Orkney, Shetland and Western Isles

<sup>&</sup>lt;sup>III</sup> Analysis of SMR1 data for 1995





Source: CRAG (1995), Management of Ovarian Cancer

The CRAG guideline is aimed at all health boards and at all gynaecologists, surgeons and oncologists involved in the management of ovarian cancer, whether they treat many or few patients. In endorsing the recommendations of the CRAG guideline, the then Chief Medical Officer stated that "all women who have the misfortune to develop cancer of the ovary should at least be able to be confident that they will receive up-to-date treatment based on sound empirical evidence"<sup>11</sup>.

A separate note on the management of ovarian cancer, written by directors of public health in Scotland, was also issued to health boards<sup>12</sup>. This note highlights the findings from audit projects undertaken in Scotland on ovarian cancer and the CRAG guideline, and puts forward a number of recommendations for commissioning ovarian cancer services (exhibit 7).

Exhibit 7: Recommendations for health boards

- Health boards should:
  - identify consultant gynaecologists with experience in the management of ovarian cancer
  - ensure, through contracts, that all patients in whom diagnosis of ovarian cancer is made are referred to an appropriate gynaecologist who can ensure that an adequate resection has been carried out
  - ensure that all patients have access to a combined gynaecology oncology service which uses appropriate chemotherapy protocols based on CRAG's guideline
  - ensure that all patients diagnosed as having ovarian cancer are registered with their regional cancer registry.
- In monitoring the care for patients with ovarian cancer, purchasers should, each year, note the number of cases diagnosed in their area. They should check that all patients have been, at some point, treated by an appropriate gynaecologist.
- Care should be administered within the context of a multidisciplinary clinic and therefore purchasers should require prospective audit of the number of chemotherapy cycles administered per patient together with the drugs involved.
- Ultimately long-term survival of patients should improve and each year purchasers should monitor one, three and five year survival figures for their cancer population.

Source: The NHS in Scotland (1995), Clinical Effectiveness

#### Report by the Scottish Cancer Co-ordinating and Advisory Committee

In May 1994, the Department of Health in England and Wales issued a consultation document concerning the commissioning of cancer services (known as the Calman/ Hine report)<sup>13</sup>. This report sets out seven basic principles which should govern the provision of cancer care (exhibit 8). Central to these proposals was the development of an integrated structure, based on a network of cancer care reaching from primary care through cancer units to cancer centres.

#### Exhibit 8: Basic principles of the Calman/Hine Report

- 1 All patients should have access to a uniformly high quality of care.
- 2 Public and professional education to help early recognition of symptoms of cancer and the availability of national screening programmes are vital.
- 3 Patients, families and carers should be given clear information about treatment options and outcomes available to them.
- 4 The development of cancer services should be patient centred.
- 5 There should be effective communication between all sectors involved with cancer services.
- 6 Psychosocial aspects of cancer care should be considered at all stages.
- 7 Cancer registration and careful monitoring of treatment and outcomes are essential.

Source: Expert Advisory Group on Cancer (1994), A Policy Framework for Commissioning Cancer Services

The general principles of the Calman/Hine report were considered and endorsed by the Scottish Cancer Co-ordinating and Advisory Committee (SCCAC) in a report which was produced in April 1996 following consultation with the NHS in Scotland<sup>14</sup>. The SCCAC report stated that cancer services should be organised so that all patients have access to an equally high standard of specialist care. Both health boards and trusts were charged with taking forward recommendations raised in the SCCAC report.

#### Scope and objectives

The review was undertaken by a small team of auditors in eight trusts and six health boards (appendix 2). These were selected on the basis of the number of ovarian cancer cases registered with each trust and health board in 1994. A short questionnaire was also sent out to all other trusts and directly managed units (DMUs). Responses were received from 22 trusts and DMUs which provide acute services (appendix 3). Of these 22, four stated that they do not deal directly with ovarian cancer patients, referring them instead to another trust for surgical and postsurgical treatment.

The main objectives of the Accounts Commission's review were to:

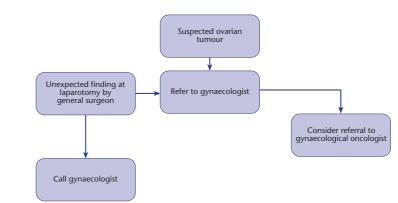
- establish how the CRAG guideline is being implemented locally
- establish whether the implementation of the guideline is being accompanied by clinical audit
- review the information which patients receive about the disease and their planned treatment
- establish how services can best be organised to ensure that the CRAG guideline can be implemented effectively
- review how health bodies are considering the recommendations of the SCCAC report on commissioning cancer services in their planning.

This report outlines the findings from the Accounts Commission review. Section 2 discusses whether trusts are organising the management of ovarian cancer in line with recommended practice, and Section 3 considers the arrangements for clinical audit. The next section looks at ways in which hospital staff communicate with patients, both verbally and in writing, and with other disciplines. Section 5 discusses the mechanisms in place within health boards and trusts for implementing guidelines at a local level, including the development of local protocols. Section 6 describes the approaches in some health boards for planning cancer services. Conclusions arising from the review are set out in Section 7.

# 2 Local implementation of the CRAG guideline

Recommended practice for the management of ovarian cancer is outlined in the CRAG guideline. However the extent to which all aspects of the guideline have been adopted in trusts which treat ovarian cancer patients varies. Designated gynaecologists have not been identified in all trusts and some patients are only referred to a specialist gynaecologist after their operation. Evidence has shown that outcome improves following post-surgical referral for multidisciplinary management, but not all trusts refer patients for this follow up.

#### Referral



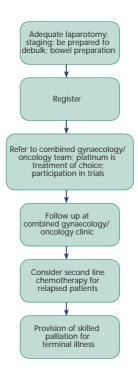
The CRAG guideline states that patients who are suspected to have ovarian cancer should be referred in the first instance to a gynaecologist, either a gynaecological oncologist or a gynaecologist with a special interest in gynaecological cancer. There is no formal definition of what is meant by 'special interest' so, for the purposes of our review, 'special interest' was taken to mean that a gynaecologist has taken a specific interest in treating patients with a gynaecological cancer and that this is recognised by their colleagues.

Thirty five percent of trusts treating patients with ovarian cancer do not have a named consultant gynaecologist with a special interest in gynaecological malignancy. This means that some patients with cancer of the ovary are not being referred to clinicians who specialise in the treatment of their disease.

Five trusts which were part of the local audits employ a gynaecological oncologist. The other three trusts have identified consultant gynaecologists with a special interest in cancer. In these eight trusts, procedures have been agreed within the gynaecology departments whereby the 'general gynaecologists' refer most cases of ovarian cancer to these 'specialist gynaecologists'. However, despite these agreed procedures some general gynaecologists continue to receive referrals of ovarian cancer, and may only refer cases on to the specialist gynaecologists post-operatively.

As far as possible, all cases of ovarian cancer should be referred to a specialist gynaecologist for treatment. Such specialists cannot treat every case, but there should be appropriate support from a designated consultant gynaecologist who can treat cases in the absence of the specialist gynaecologist and then refer cases to them post-operatively. Clear referral pathways may therefore need to be developed from primary care, within the gynaecology department, to a specialist gynaecologist. GPs should be made aware of the referral pathway for any patients whom they suspect may have this disease.

#### Treatment



#### Surgical management

Surgery to remove as much of the tumour as possible (debulking) is recommended by CRAG as the initial treatment for a patient with ovarian cancer. The guideline further recommends that surgery should be carried out by, or directly supervised by, a consultant gynaecologist.

Because of the vague symptoms of this disease, many patients may be referred initially to general surgeons. It is therefore important that general surgeons are aware of the recommendations within the CRAG guideline for calling a gynaecologist if an ovarian mass is found during laparotomy. The gynaecology departments in all eight trusts in the local audits have discussed with their general surgical colleagues the CRAG guideline and the need for ovarian cancer cases to be referred on to gynaecology for surgery. Most initial surgery on patients with cancer of the ovary at the eight trusts is performed, or directly supervised, by a consultant gynaecologist.

CRAG recommends the use of a standard form to record accurately the findings of surgery. Only four of the eight trusts use standard operation documents. These documents follow the recommendations for surgery outlined in the CRAG guideline.

It was not within the Accounts Commission's remit to review the effectiveness of surgery performed on ovarian cancer patients: rather, the Commission aimed to comment on the arrangements within trusts for ensuring procedures exist for trusts to make their own evaluation of the surgical management of patients. This can be achieved through clinical audit (see section 3).

#### Pathological assessment

The pathological assessment of the specimen removed at surgery will determine the final stage of disease and indicate further management of the patient. The pathologist has an important role in the management of ovarian cancer through the examination of tissue specimens taken from the patient during surgery to confirm the diagnosis and state the extent of any malignancy (stage of disease). Pathological information is important in planning the future management of ovarian cancer patients.

Findings from the questionnaire survey and local reviews showed that fewer than half of trusts have a consultant pathologist with a special interest in gynaecological pathology ('specialist pathologist'). Two of the eight trusts included in the local reviews do not have a pathology service on-site and so send specimens to their regional laboratory. Two trusts operate a system whereby all slides of gynaecological cancer are given a secondary review by a specialist pathologist. Three trusts have a procedure where only unusual or interesting cases are given a secondary review by a specialist pathologist. The other trust does not have a specialist pathologist. One trust included in the review has a pathology protocol for gynaecological pathology which states that a particular pathologist is required to review all cases of ovarian cancer; however, this does not always happen in practice.

Three trusts in the local reviews have at least a secondary review of ovarian cancer slides by specialist pathologists, who are members of a multidisciplinary clinic which plans the management of gynaecological cancer cases following surgery. These pathologists present cases to other members of the clinic and contribute to discussions about a patient's future management. This follows the recommended practice in the CRAG guideline that the management of ovarian cancer patients should be in collaboration with a specialist pathologist.

In general, good communication was reported between pathology and gynaecology departments, with most of the trusts included in the local review having either weekly or monthly formal meetings for these two disciplines to review cases. One trust, though, was found to have little contact between the departments.

Two pathology departments in the local reviews participate in a UK-wide external quality assessment programme for pathology which deals with cases of gynaecological oncology. Under this programme slides are circulated of cases in which an important diagnosis is expected to be made or of challenging educational cases. In this way the general standard of gynaecological pathology reporting is subjected to peer scrutiny.

#### Post-surgical management

A key recommendation of the CRAG guideline is that, following surgery, patients should be seen and followed up at a combined gynaecology oncology clinic. However, findings from the local reviews and questionnaires revealed that only 60% of trusts refer ovarian cancer patients to a combined clinic.

Because not all trusts which treat ovarian cancer patients have their own oncology department, arrangements for combined gynaecology oncology clinics vary. For example, a clinic may involve gynaecologists and oncologists within the same trust, or may be held by gynaecologists from the trust in conjunction with a visiting oncologist from the nearest oncology centre. Only six of the eight trusts in the local reviews have appropriate arrangements for referring patients for follow-up at a combined clinic. Four of the trusts either have an oncology centre on-site or else refer patients to a combined clinic held at another trust; the other two trusts have a combined clinic at their own trust which is held by the gynaecological oncologist and a visiting oncologist with a special interest in gynaecological cancer from the nearest cancer centre.

The arrangements within the remaining two trusts in the local audits do not meet recommended practice. One of these trusts, which has neither its own oncology department nor a visiting oncologist, refers only some of its ovarian cancer patients to a combined clinic held at a cancer centre since it is felt that the time at which this clinic is held makes it difficult for patients to attend. However, moves are being made at the trust to set up a combined clinic run by the trust's specialist gynaecologists and a visiting oncologist. The other trust does have an oncology department on-site but all patients receive their chemotherapy in the gynaecology department, with no referrals or discussions being made with the oncologists. This falls short of CRAG's recommended practice of referring patients with cancer of the ovary for multidisciplinary therapy following surgery. The Royal College of Obstetricians and Gynaecologists confirms this practice, citing evidence that management by a multidisciplinary team leads to a better outcome for ovarian cancer patients.

As with the move towards specialism in gynaecology in the treatment of cases of ovarian cancer so have there been similar moves in oncology. For example, the consultant oncologists at one trust in the local reviews are organised in teams, each dealing with different tumour sites. One team deals with gynaecological cancer and organises the combined clinic for patients with gynaecological cancers.

#### Chemotherapy

Following surgery, most patients with ovarian cancer will receive chemotherapy, and research has shown that patients are best treated with platinum-based chemotherapy. The local audits found that all appropriate patients are receiving platinum-based chemotherapy as first-line treatment. Where patients receive this part of their post-surgical treatment varies among trusts, with some referring patients for chemotherapy to another hospital which has an oncology department. Three of the trusts employ a gynaecological oncologist and patients have chemotherapy administered in the gynaecology ward under their management.

The Pharmacy Department within Dundee Teaching Hospitals Trust in conjunction with Gynaecology has developed a comprehensive chemotherapy profile for ovarian cancer, which is designed to assist the preparation and management of patients for chemotherapy. It also aims to help in providing staff with up-to-date information on chemotherapy regimes. An information pack has been developed for each drug used in the treatment of ovarian cancer containing information such as prescriptions with the appropriate dosage recorded and the identification of activities at particular points in the day, such as when a blood test should be taken.

A new drug in the treatment of ovarian cancer is Paclitaxel (Taxol). This drug is considerably more expensive than the usual platinum-based treatment: it costs around  $\pounds 8000$  for treatment with Paclitaxel and Cisplatin compared with just around

£1800 for Carboplatin<sup>*IVV*</sup>. Although currently its main use is as second-line treatment, Paclitaxel now has a licence as a first-line treatment for ovarian cancer which could have significant cost implications for all hospitals involved in treating this disease.

Four of the eight trusts in our local reviews provide Paclitaxel for ovarian cancer patients; the remainder refer appropriate patients to an oncology centre for this more complex treatment. Trusts which do administer Paclitaxel follow protocols for treatment, outlining which patients may be appropriate for treatment with Paclitaxel outwith the context of a clinical trial. Generally, patients who have not responded to previous platinum-based treatment are considered for Paclitaxel, with this decision usually being made by a multidisciplinary team.

#### **Clinical trials**

Research into new ways of treating ovarian cancer is continuing. Since there is currently no treatment for this disease which results in the cure of a significant proportion of patients, clinicians look for new ways to treat the disease through clinical trials. CRAG recommends that all ovarian cancer patients should be considered for entry into clinical trials. Our local reviews showed that in the five trusts which provide chemotherapy, four routinely ask eligible patients if they would consider entering a trial. The other trust in this group does not currently ask patients if they would enter a trial, since this would mean referring these patients for treatment to the oncology centre some miles away. However it is good practice to offer women the opportunity to enter clinical trials: if chemotherapeutic treatment is being provided at a district general hospital, patients could still be treated locally as part of a clinical trial co-ordinated by a cancer centre and in accordance with trial protocol.

#### Palliative care

It is important that there are arrangements in place for the provision of palliative care, where appropriate. Seven of the trusts included in the local reviews do not currently have a multidisciplinary palliative care team, although two of these do refer patients post-surgically to oncology centres which provide this service. Three trusts have recognised this gap in their service, and have established working groups to develop plans for the provision of a palliative care service within their organisation. For example, Stobhill Trust set up a workshop on palliative care which all staff were invited to attend so that their views could be sought. Following this, smaller multidisciplinary groups were established to take forward particular issues. A comprehensive booklet on the care of the dying, deceased and bereaved has since been produced, with copies held on all wards and departments within the trust.

Whilst not all trusts have their own palliative care team, all reported access to specialist palliative care provided by local hospices. In some trusts, this involves a consultant in palliative medicine providing dedicated sessions; in others arrangements can be made for a specialist to see a patient on the ward if appropriate. Three trusts employ clinical nurse specialists in palliative care whose posts are funded by the Macmillan Cancer Relief Fund. As well as providing specialist nursing care, these nurses have an important role in educating other staff on palliative care and promoting their role through seminars and workshops.

<sup>&</sup>lt;sup>IV</sup> Estimated cost for six cycles of treatment

<sup>&</sup>lt;sup>v</sup> Personal communication with hospital pharmacy manager

# 3 Clinical audit

Clinical audit is a recognised tool for improving clinical practice, yet more than one-third of trusts have not included the management of ovarian cancer in their clinical audit programme.

The aim of clinical audit is to identify areas where clinical practice may be improved and standards raised<sup>17</sup>. Results from the questionnaire and local audits showed that only around 60% of trusts are currently undertaking a clinical audit of the management of ovarian cancer or have completed an audit within the last three years. Of these, more than half are participating in an area-wide audit.

Local reviews showed that three trusts are taking part in a clinical audit co-ordinated by Greater Glasgow Health Board. All gynaecologists in another two trusts were involved in developing and undertaking clinical audit of how ovarian cancer is being managed. In two further trusts, clinical audit has been carried out by the public health department of their host health board. One of the eight trusts is not currently involved in clinical audit of ovarian cancer management.

Greater Glasgow Health Board is facilitating a clinical audit, covering all cases of ovarian cancer, and involving Glasgow's five acute trusts as well as some other trusts from neighbouring health boards. The aim of the audit is to ensure standards for ovarian cancer including:

- surgery performed by designated gynaecological surgeons
- pre-operative assessment by ultrasound
- · statement of stage of disease made in records
- · referral of patient to a multidisciplinary clinic
- entry into chemotherapy trials
- maximise the use of platinum-based treatment.

The audit involves gynaecologists and pathologists from each hospital recording pathology, surgical and post-surgical information for each patient onto summary sheets developed by a working group. The Area Clinical Audit Office then enters this information onto a database for analysis. This type of collaborative approach facilitates the sharing of information and comparisons of how ovarian cancer is being managed.

Prospective audit, such as the one being undertaken in Glasgow, has the advantage of being able to identify at diagnosis women with ovarian cancer and collect information about the progression of their disease and their treatment over time. This means that data are collected on events as they occur by people involved in the care of the patient, increasing the likelihood of data accuracy. A key benefit of this approach is the timeliness of data collection for analysis: it does not mean having to wait for cases to be registered and then extracting case notes for retrospective review.

# 4 Communication

Communication between hospital staff and patients is generally good, with patients able to discuss the management of their care privately with their consultant and other staff where possible. Written information for patients is available and some trusts have developed their own leaflets explaining the care which patients should expect to receive. Continuity of care was viewed as important but recognised as being difficult to achieve in some circumstances. Other than general surveys of patients' views of ward facilities, none of the trusts in the local audits have undertaken a review of ovarian cancer patients' opinions on the service or information provided at hospital.

Communication between different disciplines and staff groups involved in the care and treatment of ovarian cancer patients is good. Some new initiatives aimed at improving communication were identified in the local audits.

#### Communication with patients

Communicating effectively with patients can help to alleviate and reduce their anxiety and stress, and improve their experience of hospital. The Scottish Office Audit Unit's review of communication between hospitals and patients concluded that "communication is vital to the effective delivery of health care"<sup>18</sup>.

The Accounts Commission review did not directly survey ovarian cancer patients to discover how they rate communication with the hospital staff involved in their treatment and care. Instead, it reviewed what action trusts themselves are taking to investigate patients' views. None of the trusts visited had carried out a review of ovarian cancer patients' opinions on the service provided, other than some general surveys of patients' views of ward facilities. Patients' views can assist trusts in identifying where gaps in the service exist or where the service provided does not meet expectations. Relatives can also be a good source of this kind of information. A survey of ovarian cancer patients and their relatives might cover the following issues:

- Was the patient given a diagnosis?
- Who provided the patient with her diagnosis?
- Was the patient given the opportunity to discuss her diagnosis/treatment with her consultant?
- Were relatives/companions encouraged to be present during discussions with the consultant?
- What written information was the patient given about her disease?
- What information does the patient think could usefully supplement the information currently available?

Communication between hospital staff and ovarian cancer patients was reported by staff to be generally good at the eight trusts where local audits were undertaken. As far as possible, discussions with patients about their diagnosis and treatment were said to be held in private. Interviews with medical and nursing staff found that the patient is encouraged to have a companion with her during discussions about her diagnosis, treatment and future management. Consulting rooms are generally available for private discussions during clinics. Some gynaecology and oncology wards were found to have an area where discussions can be held privately, usually a single room on the ward or another room near the ward. However, some discussions are held at the patient's bedside. This was acknowledged as being far from ideal, but it is sometimes the only option when a patient is too ill to move or if a room is not available.

The local audits showed that patients are usually given their diagnosis by their consultant, who also discusses their treatment. Nursing staff have a crucial role in reinforcing what the patient has been told by their consultant, and being available on the ward to talk with the patient in more detail about her care.

The gynaecology department at Stobhill Trust has a clinical nurse specialist in gynaecological cancer who has an extremely useful role in discussing treatment with ovarian cancer patients and their relatives, overseeing the administration of their chemotherapy on the gynaecology ward, and being a source of contact at the hospital once patients have been discharged. The availability of a clinical nurse specialist, skilled and experienced in the care of women with gynaecological cancer, to co-ordinate and supervise ovarian cancer patients through their treatment is a standard recommendation in a report on the structure and function of cancer centres<sup>19</sup>.

Written information for patients is very useful for backing up verbal communication from hospital staff: patients may be very distressed when they first hear their diagnosis and may want more information later<sup>20</sup>. All eight trusts reviewed have written information for patients on ovarian cancer, although the gynaecology department within one trust had no written information on the disease. Booklets produced by BACUP were reported as being particularly informative for patients, and copies of these were available in all the trusts. Some have also developed their own leaflets. Stobhill Trust has a leaflet which was produced on a multidisciplinary basis, covering all aspects of the patient's treatment. North Ayrshire and Arran Trust has developed a leaflet for patients which deals with chemotherapy, and covers issues such as how often a patient needs to come to the hospital for treatment, potential side-effects of different drugs, details of follow-up checks and their frequency, and which staff patients should expect to see at each chemotherapy treatment.

Trusts do try to ensure that there is some continuity in who patients see each time they receive treatment at hospital. For instance, a day is set aside each week on the gynaecology ward in North Ayrshire and Arran Trust for administering chemotherapy to patients on an outpatient basis. This arrangement means that patients generally see the same staff for each chemotherapy treatment, including the consultant gynaecological oncologist. This level of continuity is more difficult to achieve in some of the larger trusts with oncology departments where it is unlikely that the patient sees their consultant at each visit due, for example, to consultants holding clinics at other trusts. However, patients may see the same nursing staff more often.

A pharmacist at North Ayrshire and Arran Trust has close involvement with ovarian cancer patients at the hospital. The pharmacist aims to speak with all ovarian cancer patients before they start chemotherapy to discuss their treatment plan, and also sees patients when they attend the gynaecology ward for chemotherapy. We did not find such close and direct involvement by this discipline in the management of ovarian cancer patients at other trusts in our review.

It is important that patients have a point of contact at hospital who they can telephone for advice and support. Patients do contact their GP once they have been discharged but many patients prefer to contact the hospital where they feel staff have more expert knowledge of their disease and its treatment. All the trusts in the local reviews provide patients with the telephone number of the ward in which they have been treated and encourage them to telephone if they are having problems. The clinical nurse specialist at Stobhill Trust acts as the main point of contact for ovarian cancer patients, and patients are encouraged to telephone her directly.

#### **Communication between disciplines**

As well as effective channels of communication between clinicians and patients, communication between clinicians and others involved in the care and treatment of patients with ovarian cancer is also important. Ovarian cancer patients may be in contact with a number of disciplines during their treatment, including gynaecology, oncology, palliative care and primary care, as well as with both medical and nursing staff. Patients should receive information consistent with that given by other people involved in their care: each discipline should be aware of the others' roles in this treatment. A multidisciplinary approach to care and treatment is therefore required, involving representatives from each of the appropriate disciplines discussing and planning treatment for each patient.

The local audits found that in general good communication exists between the various groups of staff involved in treating ovarian cancer patients. There are regular meetings, both informal and formal, between the gynaecology, pathology and oncology departments.

More than one trust may be involved with an individual patient during her treatment. As mentioned earlier, some trusts in the local reviews refer ovarian cancer patients on to another trust for post-surgical treatment. However, one such trust which follows-up some of these patients locally complains that it is not kept informed of what treatment the patient has had or what the patient has been told about the disease, treatment and prognosis.

In an attempt to develop and improve communication between the oncology centre and local hospitals which refer patients, West Glasgow Hospitals University Trust has set up monthly meetings to discuss particularly interesting cases of gynaecological cancer, which the gynaecologist and pathologist from the referring hospital are invited to attend. These meetings are also attended by members of its combined gynaecology oncology clinic, a specialist pathologist from another trust and junior medical staff, and so provide a useful forum for education and review.

Communication with the primary care team is important since patients and their families are likely to need support from their GP once discharged. The review did not seek the views of GPs on how they perceive the quality of communication with trusts in relation to patients with ovarian cancer. Instead, it focused on how gynaecologists and oncologists try to keep the GP informed of the treatment and progress of their ovarian cancer patients.

The main form of communication with GPs is through letters sent to the GP by the patient's consultant following the patient's discharge from hospital, which is routine procedure for all trusts. Other ways of providing information for GPs include:

- the combined clinic at the Royal Infirmary of Edinburgh Trust sends a letter to the GP after a patient has been seen at the clinic
- the cancer liaison sister at Stobhill Trust telephones the GP once the patient has been discharged to explain the plans for her treatment and what information the patient and her relatives have been given
- some trusts telephone the GP each time the patient has received chemotherapy to let them know about the treatment and how the patient is feeling.

Some patients require additional support following discharge from hospital and there should be a framework in place for determining the needs of individual patients and then making the appropriate arrangements. West Glasgow Hospitals University Trust provides a good example of this link between the hospital and the community, which has a liaison health visitor for medical oncology. This health visitor works in the oncology department and assesses the needs of patients either on the wards or at the combined clinic. She will then make arrangements for the patient's care at home, which can be provided by Macmillan or district nurses, or by the local social work department.

Some trusts are actively trying to improve communication. For example, North Ayrshire and Arran Trust is piloting the use of patient held records. It is hoped that these records will increase the knowledge which patients have about their health and also improve communication between people involved in their care, both in hospital and in the community. The records contain information on:

- medication records and drug allergies
- · chemotherapy treatment
- radiotherapy treatment
- clinic appointments
- nursing, paramedical and support services involved in the care of the patient
- comments from the patient's GP and the community team.

Another example of good communication between disciplines involves a chemotherapy ward in West Glasgow Hospitals University Trust which has developed an integrated care pathway for chemotherapy. This is a standard plan which outlines the usual or expected sequence and timescale of events for a patient receiving this form of treatment. The tests performed, results, observations, discharge plan etc are recorded on a pre-printed document, which is held by the patient and updated by medical, nursing and other staff involved in the patient's care. Any variance from the standard treatment is noted in the patient's document. This then provides a basis for clinical audit which may lead to a change in clinical practice. Some benefits and drawbacks of using integrated care pathways are shown in exhibit 9. Exhibit 9: Benefits, concerns and barriers to integrated care pathways

Benefits of integrated care pathways:

- Facilitate the introduction of local protocols based on research evidence into clinical practice.
- Result in more complete and accessible data collection for audit and encourage changes in practice.
- Encourage multidisciplinary communication and care planning.
- Promote more patient focused care and improve patient information by letting the patient see what is planned and what progress is expected.
- Reduce the size of case notes; less staff time spent on paperwork.
- Enable new staff to learn quickly the key interventions for specific conditions and to appreciate likely variations.
- Facilitate multidisciplinary audit and prompt incorporation of improvements in care into routine practice.

Concerns about integrated care pathways:

- · Investment of time which could be spent in other clinical activities.
- May discourage appropriate clinical judgement being applied to individual cases.
- Difficult to develop in circumstances where there are often multiple pathologies or where clinical management is very variable.
- May stifle innovation and progress.
- Need leadership, energy, good communication and time to be implemented successfully.
- Have the potential to be misused if factional health care interest have undue influence; in particular, health management may misuse them to reduce patient care costs inappropriately.

Barriers to implementation:

- Reluctance to change: this is understandable at times and should be anticipated.
- Lack of suitable existing evidence based guidelines and inadequate time and resources to develop these locally.
- Obstructive interpersonal politics.
- Lack of credit given for improvements in quality of care.
- Many management supported initiatives have been cost driven. Many of the potential benefits of implementing integrated care pathways are quality based, though cost savings have been reported.
- Attempting to change practice with partial information and no guidance or support. The person responsible for co-ordinating any care planning initiative must be sufficiently well informed and of high enough standing within the organisation.

Source: Campbell H, Hotchkiss R, Bradshaw N and Porteous M (1998), Integrated care pathways. BMJ; 316:133-137 Reproduced with kind permission of authors

# 5 Mechanisms for local implementation of guidelines

Both health boards and trusts have a role in the local development and implementation of guidelines which are produced at a national level. However, there is no general consensus on how this should be achieved.

#### Processes for guideline review

Health boards are responsible for planning and monitoring health care for their population. They therefore need mechanisms to ensure patients are being provided with care in accordance with effective clinical practice. The role suggested for health boards in ensuring the development and implementation of nationally produced guidelines at a local level has been put forward by Renvoize et al<sup>21</sup> (exhibit 10).

Exhibit 10: Health boards' role in guideline development and implementation

- Prioritise local areas of clinical need for multidisciplinary guideline development.
- Identify valid national guidelines.
- · Sponsor the tailoring of these national guidelines to local requirements.
- Ensure adequate resources for guideline development.
- · Ensure representation of key personnel in guideline development.
- · Encourage patient involvement in guideline development.
- · Incorporate guidelines into contracts and service specifications.
- Support providers in implementing guidelines.
- · Agree criteria for reviewing clinical practice based on guidelines.
- Ensure that development and implementation of guidelines is monitored, evaluated, regularly reviewed and updated.

Source: Renvoize E et al (1996), Purchasers' role in guideline development and implementation. Health Service Journal, 15 August 1996, 31

Our local reviews found no general agreement on the role of health boards in ensuring that guidelines are reviewed and implemented by local trusts. Some health boards have formal processes in place. For example, one board has established its own guidelines steering group to review and prioritise national guidelines and then includes adherence to particular national guidelines in its contracts with trusts. Other health boards regard it as the responsibility of trusts to ensure the local application of guidelines.

With specific reference to the CRAG guideline on ovarian cancer, a few health boards have no structure to assess whether patients are actually being treated by gynaecologists with a special interest in gynaecological cancer or whether patients are being referred for multidisciplinary therapy. Also, whilst the local audits found that some trusts are carrying out clinical audit of the management of ovarian cancer services, not all health boards are aware of this activity or expect to see the results.

#### Local protocol

Clinical guidelines and local protocols are increasingly recognised as the basic tools for establishing optimal local practice, for securing the best use of resources and for ensuring the best outcome for patients. Guideline development and clinical audit should be closely linked.

In our local reviews at trusts, we found that there is no common structure for the local implementation of national guidelines (such as those from SIGN<sup>VI</sup> and CRAG). For example, one trust has no formal process for reviewing and implementing national guidelines; another sets up working groups to consider individual guidelines as they are produced; a group of lead clinicians within another trust discusses national guidelines and then passes them to an appropriate clinician within the trust to take forward; and a fourth trust has established a clinical effectiveness group which reviews all national guidelines with responsibility for their implementation delegated to appropriate individuals within the trust. West Glasgow Hospitals University Trust has developed a comprehensive framework for the local implementation of national guidelines which reflects the good practice recommended by CRAG.

The process for the local implementation of national guidelines at West Glasgow Hospitals University Trust involves a committee, comprising members of the trust's clinical audit committee and lead clinicians, first considering whether a national guideline is appropriate for adoption within the trust. This decision-making process includes: considering whether the national guideline is scientifically valid and evidence based; reviewing how the guideline compares with local practice; and establishing the resource implications of implementing and auditing the guideline. A local protocol is then developed and distributed to appropriate staff. Six months later an audit is undertaken to establish whether the national guidance has been implemented effectively and whether change in practice has occurred. Clinicians affected by the guideline are consulted throughout this process.

The Chief Medical Officer in post when the CRAG guideline was published recommended that the principles embodied in the guideline should be adopted in all hospitals involved in the treatment of the disease. However, findings from our questionnaire and local reviews reveal that of the 26 trusts which treat cases of ovarian cancer, only ten have developed a local protocol for this disease. Two trusts in our local reviews use a local protocol developed by members of a multi-disciplinary clinic dealing with cases of gynaecological cancer; a further trust established a multidisciplinary group to develop a local protocol. Three other trusts included in our local reviews stated that they view the CRAG guideline itself to be comprehensive and straightforward, consider the recommended practice to be followed within the organisation, and accordingly have adopted this document as their local protocol. The local reviews did reveal one trust which had developed a local protocol for the management of ovarian cancer in the early 1980s but there was no evidence of any update after publication of the national guideline.

<sup>&</sup>lt;sup>VI</sup>Scottish Intercollegiate Guidelines Network

### 6 Planning cancer services

Health boards and trusts are taking a collaborative approach to developing an integrated framework for cancer services in response to the SCCAC report. Some health boards have set up multidisciplinary groups to focus on developing services for particular tumour sites, including the gynaecological cancers, which involve local specialists.

Health boards and trusts are taking a collaborative approach in developing an integrated framework for cancer services. Health boards and trusts in the North East, South East and West of Scotland have all established regional groups. For example, membership of the South East Scotland Cancer Group is multidisciplinary including representatives from public health, clinical audit, oncology, various surgical specialties, nursing and general practice. The remit of the group includes developing clinical advice on individual cancers, considering clinical audit issues, and developing options for the provision of services.

Health boards have also set up groups within their own locality to consider issues raised in the SCCAC report, for example, the Cancer Services Review Group in Grampian. These groups also involve local clinicians. Sub-groups for particular cancers have also been established in some health boards to review current services and develop frameworks for the provision of services in line with recommendations in the SCCAC report and other relevant guidance. Four health boards in the local reviews have set up groups which focus on gynaecological cancer.

Assessments of gynaecological cancers, including cancer of the ovary, have been undertaken in four heath boards. This has enabled them to identify incidence within their locality and outline plans for services around current and future requirements. Two health boards have not carried out such an assessment or produced a profile of the current pattern of services for gynaecological cancers.

The Acute Services Review, which is currently underway, will also have an impact on cancer services. Its recommendations are likely to affect both the organisation of services and the approaches to quality assurance and accreditation.

# 7 Conclusions

Whilst a national guideline on how ovarian cancer should be managed has been in existence since 1995, not all trusts which treat patients with this disease have procedures for managing their treatment in accordance with all its recommendations. In particular, not all trusts have a named consultant gynaecologist with a special interest in gynaecological malignancy, and the referral of patients to a combined gynaecology oncology clinic is not uniform practice. Some patients are also not being asked if they would consider entry into clinical trials, despite this being one of the key recommendations of the CRAG guideline.

Clear referral pathways from primary care, through to gynaecology, and on to joint post-surgical management are lacking. Some gynaecologists continue to receive referrals from primary care and do not pass them on to a designated specialist gynaecologist. Only around 60% of trusts refer patients with ovarian cancer to a combined gynaecology oncology clinic despite evidence that outcome is improved where patients are managed by this type of clinic, which provides a multi-disciplinary approach to post-surgical care.

Generally, there is good communication between hospital staff and patients, with nurses in particular having an important role as a source of information and support. Communication was also reported to be good between the disciplines involved in the care of ovarian cancer patients.

Despite evidence-based guidelines being produced by organisations such as CRAG and SIGN, often there is no framework within health boards for ensuring that the recommended practice for treating patients is being implemented successfully by trusts. One way of achieving this, which was found at one of our study sites, is to facilitate a clinical audit of adherence to recommended practice, with findings shared by both health boards and trusts. Such an arrangement is a useful way of ensuring that treatment is being administered in line with best practice, and where there is evidence that this falls short in a particular area then steps can be taken to improve this. However, not all trusts and health boards audit the management of ovarian cancer, despite the existence of a national guideline which sets the standard for treatment.

Within trusts, there is no common structure for implementing national guidelines at a local level although, in general, trusts do have a framework for considering these and taking them forward locally where considered appropriate. Prospective audit is a useful tool for measuring compliance with recommended practice over time and is being applied to the management of ovarian cancer in some trusts.

Health boards and trusts are taking a collaborative approach in the development of cancer services, with hospital clinicians, nurses and GPs among others being involved and consulted in plans for the future provision of services. Groups have also been established which focus particularly on the gynaecological cancers, and the CRAG guideline on the management of cancer of the ovary is being considered and taken forward in this forum.

In summary, the CRAG guideline is not being fully applied in all trusts treating patients with ovarian cancer, so that some women do not have full access to the recommended treatment. This disparity should be addressed through the groups which health boards are establishing to take forward the recommendations of the SCCAC report. Groups set up to focus on gynaecological cancer, involving local clinicians and other professionals, will also help to ensure that services are organised in line with the guideline and women receive the best possible care.

### Appendix 1: Advisory panel

Dr E Junor	Consultant Oncologist Beatson Oncology Centre West Glasgow Hospitals University NHS Trust
Dr A Williams	Senior Lecturer in Pathology University of Edinburgh
Ms J McKenzie	Acting Directorate Manager Beatson Oncology Centre West Glasgow Hospitals University NHS Trust
Dr E Walker	Consultant Gynaecologist Crosshouse Hospital North Ayrshire and Arran NHS Trust
Dr A Wallace	Consultant in Public Health Medicine Lothian Health Board

# Appendix 2: List of study sites

NHS Trusts	Health Boards
Aberdeen Royal Hospitals NHS Trust	Argyll & Clyde Health Board
Dundee Teaching Hospitals NHS Trust	Fife Health Board
East & Midlothian NHS Trust	Grampian Health Board
Kirkcaldy Acute Hospitals NHS Trust	Greater Glasgow Health Board
North Ayrshire & Arran NHS Trust	Lanarkshire Health Board
Royal Infirmary of Edinburgh NHS Trust	Lothian Health Board
Stobhill NHS Trust	
West Glasgow Hospitals University NHS Trust	

# Appendix 3: Questionnaire responses

Questionnaires were received from the following trusts and directly managed units.

Angus NHS Trust	Moray Health Services NHS Trust
Borders General Hospital NHS Trust	Orkney Health Unit
Caithness & Sutherland NHS Trust	Perth & Kinross Healthcare NHS Trust
Dumfries & Galloway Acute & Maternity Hospitals NHS Trust	Raigmore Hospital NHS Trust
Falkirk & District Royal Infirmary NHS Trust	Shetland Hospitals & Community Services Unit
Glasgow Royal Infirmary University NHS Trust	South Ayrshire Hospitals NHS Trust
Hairmyres and Stonehouse Hospitals NHS Trust	Southern General Hospital NHS Trust
Inverclyde Royal NHS Trust	Stirling Royal Infirmary NHS Trust
Law Hospital NHS Trust	Victoria Infirmary NHS Trust
Lomond Healthcare NHS Trust	Western General Hospitals NHS Trust
Monklands & Bellshill Hospitals NHS Trusts	Western Isles Health Unit

# Appendix 4: Glossary

BACUP	British Association of Cancer United Patients.
Chemotherapy	Use of anti-cancer (cytotoxic) drugs to destroy cancer cells.
Clinical audit	The systematic, critical analysis of the quality of clinical care.
Clinical guideline	Systematically developed statements which assist in decision making about appropriate health care for specific clinical conditions.
Combined clinic	A clinic for the post-surgical management of patients by a team which includes a gynaecologist with a special interest in oncology and a non-surgical oncologist with an interest in gynaecological malignancies.
Debulking	Removing as much of the tumour as possible during surgery.
Gynaecology	The branch of medical science which deals with diseases specific to women.
Gynaecological oncologist	A gynaecologist with additional training in oncology.
Hospital episodes	Admissions, including day admissions, to hospital, involving the completion of an SMR1 data collection form on discharge.
Integrated care pathway	Multidisciplinary approach to treating patients with a particular condition where treatment is planned, recorded and reviewed on a single document for individual patients.
Laparotomy	Operation in which the abdominal cavity is opened.
Oncology	The branch of medical science which is concerned with the management of malignant disease such as cancer.
Paclitaxel	Form of chemotherapy for advanced ovarian cancer: it is also known by its trade name, Taxol.
Palliative	Term applied to the treatment of incurable diseases, in which the aim is to mitigate the sufferings of the patient, not to effect cure.
Pathology	The science which deals with the causes of, and changes produced in the body by, disease.
Prospective audit	An evaluation of care by criteria agreed before the care is provided.
Protocol	An adaptation of a clinical guideline to meet local conditions and constraints.

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