

This vision does not represent government policy but provides useful insight into how gynaecological cancer services might develop over the next 5 years

Annex D

Gynaecological Cancers 2012

Epidemiology

1. It is estimated that there will be an increase in the incidence of gynaecological cancers by 2012. For example:
 - a) The incidence of cervical cancer is likely to increase despite the national screening programme because of a reduction in the uptake of cervical screening in younger women. In addition, it is possible that the large influx of women from Eastern European countries, expected to continue over the next 5 years, will add to the number of cervical cancers diagnosed in the United Kingdom. Women from Eastern Europe and other ethnic minorities should be actively encouraged to partake in the screening programme, requiring engagement of primary health care and the public health services.
 - b) The incidence of reported ovarian cancer may continue to increase due to further improvement in diagnosis and referral to gynae multi-disciplinary teams from other hospital disciplines such as care of the elderly & general surgery. The true incidence will also increase with an aging population.
 - c) The incidence of endometrial cancer will increase overall, as a consequence of an aging population, the reduction in hysterectomy rates and the increasing rate of obesity.
 - d) The incidence of vulval & vaginal cancers will likely increase due to a probable increase in prevalence of infections with oncogenic HPV (main risk factor for young women) and an aging population.

Prevention

2. The gynaecological community recommends the introduction of an HPV vaccination programme to reduce the risk of cervical cancer and HPV-related vulval and vaginal cancers. There will not be an impact on clinical services (need for screening, referral to colposcopy, cancer incidence) by 2012 from a vaccination programme involving immunization of late primary / early secondary school aged girls. Whilst a vaccination programme will need to be supported by a public health campaign to highlight the causes of cervical cancer, we would also support a public health campaign to promote the importance of attending for regular screening, targeting the 25-29 age group in particular.
3. Regional genetics services should be readily available for all women from suspected high risk families (BRCA 1 or 2 gene mutations and HNPCC families). More women will have been identified with a higher genetic risk of ovarian cancer by 2012 (mainly BRCA 1 or 2 gene mutations) – this is likely to have an impact on the NHS in terms of increased demand for laparoscopic prophylactic salpingo-oophorectomy surgery (removal of the ovaries and fallopian tubes).

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Screening

Cervical

4. By the end of 2008 all cervical screening services should have moved to liquid based cytology (LBC) and the number of inadequate tests should have fallen.
5. There will be increased interest in providing some colposcopy services (to manage abnormal cervical cytology tests) in the community by 2012. It is important to ensure that units and clinicians performing colposcopy in the community are adequately trained and certified and subject to the Cervical Screening Programme quality assurance programme. Different models may be possible including colposcopy in the independent sector, outreach from district general hospitals and trained GPs/other staff conducting colposcopy services in the community.
6. Research evidence supports the use of HPV testing to triage low grade cytological abnormalities and as a test for cure following treatment. These will accelerate the colposcopic diagnosis for those who are at risk and accelerate return to call / recall for those who are not at risk.

Ovarian

7. Data from the ovarian cancer screening trial (UKCTOCS) will not be available to influence policy before 2012. Decisions regarding the implementation of an ovarian cancer screening programme cannot be made until the results of this study are published.
8. Symptom screening is being assessed in a parallel study to UKCTOCS. In preliminary stages at present, the results of this study will not be available to influence policy before 2012.

Diagnostics

9. Clearly defined clinical pathways, improved information systems and MDT processes between diagnostic cancer units (locality teams) and cancer centres (specialist teams) with regards radiology and pathology may reduce duplication which exists in some cancer networks.
10. GPs will likely have greater access to diagnostic tests by 2012. An increased use of ultrasound will lead to the diagnosis of more benign conditions with a resulting impact on NHS services to assess and manage these.
11. Diagnostic teams (rapid access clinics) will be included for assessment in the next round of the peer review process.
12. There is likely to be an increased emphasis on diagnostic clinics and investigations in primary care / community settings and the independent sector. Appropriate training and quality assurance for all diagnostic ultrasound services is important, to ensure

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high quality scanning and avoid unnecessary referral of patients to secondary care specialist services for management of low risk / physiological ovarian cysts.

13. Assessment of post-menopausal bleeding by ultrasound and endometrial biopsy is an example of a routine diagnostic service which may be appropriate in the independent sector and some community settings, provided that training and quality assurance are ensured.
14. There are no major changes expected by 2012 regarding imaging modalities for gynaecological cancers, excepting that evidence might emerge to support more use of PET-CT.

Treatment

15. Analysis and rationalisation of “inpatient” care pathways, associated with redesign and improvements to other processes within acute hospital trusts, may result in a reduction of the average length of stay for many surgical procedures and other inpatient treatments. It is predicted that by 2012:
 - There may be a greater reliance on neo-adjuvant chemotherapy and interval debulking surgery, although clear evidence supporting this development is lacking. Randomised clinical trials assessing this question (EORTC 55971 and CHORUS) will impact on practice.
 - Radical cytoreductive surgery will likely become more established.
 - There will also be more use of surgery for selected cases of recurrent disease and a possible increase in palliative surgery.
 - The role of intraperitoneal chemotherapy (where chemotherapy is infused into the peritoneal cavity following surgery) is being evaluated and may become established in the UK by 2012. This development would have resource implications for cancer centres to be able offer the service. Gynae Network Site Specific Groups (NSSGs) would need to decide whether ovarian cancer surgery and intraperitoneal chemotherapy should be offered in every gynae cancer centre or whether it should be centralised, possibly within a “network of networks”.
 - The roles of targeted therapies (eg growth factor inhibitors) in primary treatment and maintenance therapy are being evaluated and may become established in the UK by 2012.
 - There is likely to be a massive increase in the costs of medical treatments for ovarian cancer, particularly if targeted therapies are shown to be effective in this disease.

17. For *cervical* cancer:

- Chemoradiotherapy (radiotherapy and concomitant chemotherapy) will remain the mainstay of primary treatment for advanced disease and standard adjuvant therapy for high-risk cases following surgery. Adequate radiotherapy facilities must be available for patients in all regions of the country to ensure that timely treatment can be administered in both the primary and adjuvant setting.

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- Following further evaluation of case series and establishment of clinical trials, greater utilisation of minimal access (laparoscopic) surgery for early stage cervical cancer management is predicted, including laparoscopic lymphadenectomy, total laparoscopic radical hysterectomy, laparoscopically assisted radical vaginal hysterectomy & fertility-sparing radical trachelectomy. Adequate training opportunities in minimal access surgery should be available for all subspecialty gynae oncology trainees. An increase in the use of minimal access surgery would be expected to lead to shortened “inpatient” hospital stays.

18. For **endometrial** cancer:

- There will be the need to utilise increasing resources; the patients are challenging to treat, with co-morbidities including obesity and multiple medical problems.
- The role of lymphadenectomy remains contentious with opposing interpretation of the evidence and hence differing schools of practice within the gynae oncology community.
- There is likely to be a greater utilisation of minimal access (laparoscopic) surgery for endometrial cancer management.
- The role of chemoradiation (chemotherapy with radiotherapy) in place of radiotherapy is being evaluated and may be established in the UK by 2012. There is likely to be an increased use of cytotoxic chemotherapy in both adjuvant treatment and advanced disease.

19. For **vulval** cancer:

- The use of sentinel lymph node assessment is likely to become established in clinical practice following assessment in the research setting. For some patients, this may avoid the need for full inguinofemoral (groin) lymph node dissection, which is associated with significant treatment-related morbidity.
- Whilst reconstructive surgery does not play a major role in vulval cancer surgery at the present time, there may be an emerging role over the next 5 years, reflecting the change in practice in breast cancer surgery over recent years.

20. For **rare tumour types / uncommon or highly specialised procedures**, we anticipate that supra-regional referral pathways will be established, probably within “networks of networks”. Integration of services between neighbouring networks is viewed as a natural progression from the “Improving Outcomes” model. A specific large gynae oncology centre within a group of networks may be nominated to manage certain types of cases, to ensure adequate clinical through-put to develop and maintain skills and specialist services. A list of conditions / procedures would be agreed by the network groups and will be dependent on clinical incidence and service configuration within individual networks, geography & available expertise. For example, conditions & treatments for possible consideration for supra-regional referral pathways might include germ cell tumours, brachytherapy, post-radiation exenteration & radical trachelectomy.

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Supportive & Palliative Care

21. Psychological (particularly psychosexual) support is very patchy and needs to be addressed urgently. Increased resources will be required by 2012.
22. With an improved palliative care infrastructure, it is possible that paracentesis (drainage of ascites from the peritoneal cavity) and other palliative procedures may be able to be performed in the community.
23. Attention should be paid to programmes offering support for women living with adverse physical and / or psychological quality of life impact from chronic gynae oncology disease and treatment-related side effects. Initiatives may include programmes of holistic supportive care, survivorship and rehabilitation programmes.
24. Where appropriate, women should be offered access to specialist fertility services on the NHS to explore the potential of new technologies eg oocyte and ovarian cryopreservation.

Follow up

25. A systematic review of research evidence regarding follow-up for all cancers will be commissioned by the Cancer Action Team. The FIGURE study to compare routine scheduled follow-up with patient initiated follow-up is unlikely to publish results in time to influence policy before 2012. A hybrid model of limited scheduled appointments augmented by patient initiated follow-up was supported by the Gynae NSSG Leads group and has been implemented in a number of networks. Rationalisation of follow-up will likely be required in many networks before 2012.
26. Trials into alternative models of follow-up (web-based, telephone, email etc) should be supported and the possibility for positioning follow-up programmes within the community should be explored.

Service Configuration

27. The configuration of existing gynaecological cancer services is based on the IOG published in July 1999 and this will remain the basic structure for services in 2012. However, new research evidence / accepted clinical guidelines will render aspects of the IOG obsolete and these should be identified by the profession. Over-riding guidance in these particular areas will be produced. The British Gynaecological Cancer Society (BGCS), the Gynae NSSG Leads Group and the BGCS/NSSG Leads Guidelines Group will continue to inform NICE on review topics relevant to gynae oncology. A Cochrane collaboration of gynae oncology topics will promote the research evidence for new guidelines.
28. In some networks, cancer unit MDT's cannot be adequately supported with provision of consultant pathology, radiology and oncology services. Furthermore, duplication of pathology and radiology review in both locality (cancer unit) MDT and specialty (cancer centre) MDT can delay the referral / treatment pathway. The revised peer review measures (assessable standards) for gynae oncology will support an alternative

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configuration model. Former “units” may perform a diagnostic role without a separate dedicated MDT, whilst the lead clinician is linked to the “centre” MDT as a core member. Providing he / she fulfils requirements of core membership, appropriate low risk endometrial cancer surgery formally done by him / her can be retained in the locality, functioning as an extension of the “centre” specialty team.

29. Networks should consider closer working relationships to facilitate the management of rare tumours and the provision of more difficult management strategies, thus fully utilising all of their available expertise. It is expected that some networks may review service configuration, working towards larger cancer centres. The group advises that flexibility is maintained regarding configuration of services, so that networks can tailor the optimal configuration of services for patient care within the network, operating within the confines of IOG and peer review guidelines.

Underpinning Programmes

Workforce & Training

30. The gynaecological cancer IOG recommended at least 2 gynaecology oncologists per million population: a formula predicting approximately 100 new cancers annually per gynae oncologist. However, workload demands have changed significantly over the past decade, driven by a number of factors including multi-disciplinary team working, administration, targets, peer review, training, European working time directive, the new consultant contract, consultant-led service with loss of clinical support from junior and middle grade staff, less experienced middle grade staff, increased centralisation of low risk oncology surgery & complex benign surgery to gynae oncology teams in many networks and increased complex specialised surgery.
31. Furthermore, the incidence of some gynaecological cancers continues to increase (see above). As a result most gynaecological oncologists work far in excess of the desired 10 PA's and appropriate time for training, service development, research & professional development is lacking. An analysis of gynae oncology manpower requirements in Scotland was performed for the RCOG in 2005 (The Future of Obstetrics and Gynaecology in Scotland: Service Provision and Workforce Planning. Scottish Committee of the RCOG, 2005). This concluded that 16 whole time equivalents (wte) gynaecological oncologists are required for the population of Scotland (around 3 per million population), whilst some gynae oncology workload continues to be done by non-subspecialist “special interest consultants”. A survey by the Gynae NSSG Leads Group in 2006 revealed that a large majority of Gynae NSSG Leads believe that 3 or 4 gynae oncologists are required per million population. The group recommends 3.5 wte subspecialist gynae oncologists per one million population. This will have a significant impact on resource allocation, manpower planning and training during the next 5 years. Adequate subspecialist consultant staffing should be included as a measurable standard for the peer review process and the gynae oncology community urges the provision of 3.5 wte gynae oncologists per one million population to be incorporated as a measurable target for the next round of peer review assessments.
32. The number of trainees admitted to subspecialty training should be tailored to cater for predicted consultant posts. Without a major consultant expansion (see above), the

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survey conducted by the NSSG Leads group suggests that current rates of subspecialty training will likely produce an oversupply of gynae oncologists by 2012. Training subspecialists with little prospect of attaining a subspecialist consultant post may potentially destabilise cancer network referral pathways if these individuals are forced to apply for locality “unit lead” consultant posts.

33. The adoption of adequate gynae oncology manpower would create possibilities for extended training and professional development at all phases of a gynae oncologist’s career, such as a sabbatical to enable training in a new surgical procedure (eg laparoscopic procedures, ovarian cancer radical cytoreductive surgery).
34. For safe clinical practice, the group recognises that gynae oncology teams must be adequately supported by middle grade medical staff. Dedicated surgical care nurse practitioner support may substitute in part for middle grade medical staff. Middle grade support should be included as a measurable standard for peer review.
35. Whilst (surgical) gynae oncologists undergo a formal subspecialisation training programme (recognised by the GMC), formal subspecialist gynae oncology training programmes do not exist for the other core specialties within the multi-disciplinary teams (medical & clinical oncologists, pathologists & radiologists). Structured training and educational programmes for the other core gynae oncology related disciplines would be supported. A post-FRCR training year for clinical oncologists can be spent in the gynae oncology subspecialty discipline, but training experience in specialty fields such as brachytherapy are sometimes limited. Co-ordinated training posts within a “network of networks” may address this problem. A module in oncology is being developed by the RCOG for general gynaecologists preparing for a “locality / unit lead” consultant post. It is acknowledged that much gynae oncology training, particularly in non-surgical specialties that do not have formalised “subspecialty” training programmes, takes place during the first few years of a consultant post. All new consultants should have the support of experienced colleagues rather than be appointed into single-handed posts. Manpower requirements and planning for non-surgical disciplines should be addressed. It is recognised that advancements in diagnostic techniques are likely to place a strain on pathology services in particular. The above represents the view of the BGCS and NSSG leads but does not necessarily represent the positions of the relevant royal colleges.
36. Some more general workforce / training issues that need to be addressed by 2012 are:
 - Investment is required for psychology and psychosexual counselling in many networks (see above). Services across the country are patchy at present. Formal pathways for these services should be established in all networks.
 - The role of academic gynaecologists must be recognised and supported – there is consensus that academic medicine is “in crisis” with limited career progression & limited funding opportunities.
 - There is disagreement whether gynaecological oncologists and gynae oncology services should be managed within gynaecology & obstetrics, oncology or surgical directorates. At least until 2012, this should remain a local decision.

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- There is a need for clarity about the role of the cancer nurse specialist (including how it relates to various nurse practitioner models) and a means to demonstrate the productivity of this role, to avoid it being a “soft” target for budget cuts. The Clinical Nurse Specialist is acknowledged as an essential and integral member of the gynae oncology multi-disciplinary team, and there is recognition within the gynae oncology community of the added value they bring to the patient’s cancer experience. Every woman diagnosed with gynaecological malignancy must have ready access to the services of a Clinical Nurse Specialist.

Information / Benchmarking

37. By 2012 it should be mandatory for the NHS to collect data on gynaecological (and other) cancers and for outcomes measures to be published by the Healthcare Commission at a national level for public scrutiny. Centres & networks must be able to provide data on incidence of cancers, recurrence & survival data, complications & treatment-related morbidity and trials recruitment. Significant investment in administrative and IT systems is likely to be required for this data to be captured in a valid and reliable manner and analysed nationally.
38. The NSSG Leads Group and BGCS have commenced work on benchmarking standards and outcome measures, having already compiled an agreed list of benchmarking standards using the Delphi technique. A BGCS / NSSG Leads working group will develop a national audit / pilot to establish standard complication statistics for gynae oncology practice and identify mechanisms for centres / units to collect this data in a robust and reliable way in clinical practice. The group will liaise with the RCOG & Healthcare Commission.
39. Once mechanisms for collecting and analysing benchmarking data are established, these data must become integrated into the peer review process.
40. As a guide to networks when considering possible supra-regional referral for rare procedures, the group suggests that to maintain skills, a gynae oncologist should perform, teach or assist all surgical procedures within his / her practice a minimum 6 times per year.
41. Central databases for rare tumours (eg germ cell tumours) and uncommon / novel procedures (eg radical trachelectomy for cervical cancer) should be maintained, with mandatory registration of cases, to enable specialist national audit, ensure consistent quality of care nationally and promote research.

Clinical Trials

42. Clinical trials programmes should be coordinated across networks and ideally across “networks of networks”. All centres and units must have adequate provision of clinical research nurse resources to facilitate trials recruitment.
43. Integration of trials activity between the National Cancer Research Institute (NCRI), Cochrane and the BGCS will assist in trials development and improve recruitment.

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Miscellaneous

44. Primary peritoneal cancer (cancer of the abdominal cavity) presents like advanced stage ovarian cancer and is managed by gynae oncology teams. The diagnosis can only be made on histological assessment of the ovaries and when neoadjuvant chemotherapy is employed it is often not possible to determine confidently whether the tumour was initially ovarian or primary peritoneal. Currently primary peritoneal cancer is not coded as a gynaecological cancer. The group believes that this should be revised and primary peritoneal cancer officially recognised within the remit of gynae oncology.

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