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 2015

Epidemiology

1. It is estimated that there will be an increase in the incidence of gynaecological cancers by 2015. 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. There will not yet be an impact on incidence of cervical cancer and HPV-related vulval and vaginal cancers or on clinical services (need for screening, referral to colposcopy, cancer incidence) by 2015 from the HPV vaccination programme.

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 2015 (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).

Screening and early detection

4. Key messages on the signs and symptoms for all individual gynaecological cancers are being developed and consideration will be given as to whether it is possible to develop a number of these into some core signs and symptom messages for gynaecological cancer.

5. Further research will be carried out to understand the complex barriers to early presentation with gynaecological cancers amongst women so that awareness campaigns can be effectively targeted.

Cervical

6. A public health campaign will be implemented to promote the importance of attending for regular cervical screening, targeting the 25-29 age group in particular.

7. All cervical screening services will have moved to liquid based cytology (LBC) and the number of inadequate tests will have fallen.

8. There will be increased interest in providing some colposcopy services (to manage abnormal cervical cytology tests) in the community by 2015. 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.

9. 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

10. Guidance on the recognition and initial management of ovarian cancer will be issued by NICE in 2011, aiming to achieve a greater proportion of women being diagnosed with ovarian cancer at an earlier stage. Ovarian cancer awareness will be regularly measured through the use of NAEDI's ovarian cancer awareness measurement tool. Targeted awareness campaigns in GPs and women at risk of ovarian cancer will increase the number of women with knowledge of the signs and symptoms of this disease.

11. Data from the ovarian cancer screening trial (UKCTOCS) will not be available to influence policy before 2015**.** Decisions regarding the implementation of an ovarian cancer screening programme cannot be made until the results of this study are published. However, results of the UKFOCSS trial on screening women with an elevated familial risk of ovarian cancer may be available as early as 2012 and should inform a discussion as to whether women in this risk category should be offered regular screening.

12. 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 2015.

<u>Diagnostics</u>

13. 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 areas.

14. GPs will likely have greater access to diagnostic tests by 2015. 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.

15. Diagnostic teams (rapid access clinics) will be included for assessment in the peer review process.

16. 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 high quality scanning and avoid unnecessary referral of patients to secondary care specialist services for management of low risk / physiological ovarian cysts. Care must be taken that an increased reliance on primary care and the independent sector does not erode quality or create an inefficient service with high overheads and ineffective use of equipment and personnel.

17. There are no major changes expected by 2015 regarding imaging modalities for gynaecological cancers, excepting that evidence might emerge to support more use of PET-CT.

<u>Treatment</u>

18. 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 2015:

19. For ***ovarian*** cancer:
    a. There may be a greater reliance on neo-adjuvant chemotherapy and interval debulking surgery. Randomised clinical trials assessing this question (EORTC 55971 and CHORUS) will impact on practice.
    b. Radical cytoreductive surgery may become more established, possibly with initial laparoscopy to assess operability.
    c. There will also be more use of surgery for selected cases of recurrent disease and a possible increase in palliative surgery.
    d. Use of ascites triage services or day case paracentesis will reduce episodes in hospital.
    e. 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 2015. This development would have resource implications for cancer centres to be able to offer the service. Appropriate training would need to be given and services organised to best deliver this service. It would need to be decided whether ovarian cancer surgery and

intraperitoneal chemotherapy should be offered in every gynae cancer centre or whether it should be centralised.

f. 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 2015.

g. 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. There may be a demand for access to Avastin as a life-extending treatment for women with ovarian cancer if results from the GOG and ICON7 trials are positive.

20. For ***cervical*** cancer:
    a. 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.
    b. 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.

21. For ***endometrial*** cancer:
    a. There will be the need to utilise increasing resources; the patients are challenging to treat, with co-morbidities including obesity and multiple medical problems.
    b. The role of lymphadenectomy remains contentious with opposing interpretation of the evidence and hence differing schools of practice within the gynae oncology community.
    c. There is likely to be a greater utilisation of minimal access (laparoscopic) surgery for endometrial cancer management.
    d. The role of chemoirradiation (chemotherapy with radiotherapy) in place of radiotherapy is being evaluated and may be established in the UK by 2015. There is likely to be an increased use of cytotoxic chemotherapy in both adjuvant treatment and advanced disease.

22. For ***vulval*** cancer:
    a. 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.

b. 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.

23. For ***rare tumour types / uncommon or highly specialised procedures***, we anticipate that supra-regional referral pathways will be established. Integration of services between neighbouring areas is viewed as a natural progression from the "Improving Outcomes" model. There should only be a handful of centres throughout the UK dealing with certain rare rumour types or uncommon or highly specialised procedures and referral pathways will be established to facilitate this. A specific large gynae oncology centre within a larger area 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 and will be dependent on clinical incidence and service configuration within individual areas, geography & available expertise. For example, conditions & treatments for possible consideration for supra-regional referral pathways might include immature germ cell tumours of the ovary and other rare ovarian tumours, melanoma of the vulva, post-radiation exenteration & radical trachelectomy. Robust data analysis will be required to assess clinical throughput and outcomes for these rare tumours and procedures and determine the appropriate number of centres required to optimise care. The models utilised should reflect the incidence and idiosyncrasies of the rare tumours and procedures, but may reflect the present centralised models of care for gestational trophoblastic disease and pseudomyxoma peritoneii.

<u>Supportive & Palliative Care</u>

24. Psychological (particularly psychosexual) support is very patchy and needs to be addressed urgently. Increased resources will be required by 2015. All women with newly diagnosed gynaecological cancer should be given information and support on psychosocial and psychosexual issues. Psychosexual and late effect assessment and support clinics for women who have undergone pelvic radiotherapy will become standard practice.

25. A greater emphasis will be placed on meeting the holistic needs of women with gynaecological cancer, helping them to "live well" with their cancer. Clinical nurse specialists will play an important role in delivering this aspect of care. The introduction of Information Prescriptions, which already have an established Gynaecological Cancer Pathway will help with access to information.

26. There will be more equitable access to palliative care services. 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.

27. 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.

28. 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

29. Rationalisation of follow-up will likely be required in many localities before 2015. Patient Reported Outcome Measures (PROMs) will be developed and validated in gynaecological oncology services, and may prove effective in rationalisation of follow-up to improve targeted care for patients and efficient use of resources.

30. Some centres have already implemented new systems for follow-up including open access "patient initiated" follow-up and reduction in routine follow-up, which have proved to be cost-effective. Results of the recent OV05 ovarian cancer follow-up trial showed no benefit to intervening with chemotherapy for asymptomatic women on the basis of a rising CA125, and the routine use of Ca125 surveillance in follow-up should be reviewed. 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

31. 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 2015. 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.

32. In some areas, 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 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.

33. Local areas 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 local areas may review service configuration, working towards larger cancer centres. The group advises that flexibility is maintained regarding configuration of services, so that local areas can tailor the optimal configuration of services for patient care within the area, operating within the confines of IOG and peer review guidelines.

Underpinning Programmes

Workforce & Training

34. 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 areas and increased complex specialised surgery.

35. 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.

36. 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 survey conducted by the NSSG Leads group suggests that current rates of subspecialty training will likely produce an oversupply of gynae oncologists by 2015. Training subspecialists with little prospect of attaining a subspecialist consultant post may potentially destabilise referral pathways if these individuals are forced to apply for locality "unit lead" consultant posts.

37. 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).

38. 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.

39. 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 wider area 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.

40. Some more general workforce / training issues that need to be addressed by 2015 are:
    a. Investment is required for psychology and psychosexual counselling in many localities. Services across the country are patchy at present. Formal pathways for these services should be established in all localities.

b. 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.
c. There is disagreement whether gynaecological oncologists and gynae oncology services should be managed within gynaecology & obstetrics, oncology or surgical directorates. At least until 2015, this should remain a local decision.
d. 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. For example, in the Target Ovarian Cancer Pathfinder Study (2009) women with ovarian cancer cited their gynae cancer clinical nurse specialist as the single most helpful healthcare professional role in terms of supporting their emotional needs. Every woman diagnosed with gynaecological malignancy must have ready access to the services of a clinical nurse specialist. Investment should be made at a trust level to ensure adequate clinical nurse specialist cover and adequate training and support to allow clinical nurse specialists to carry out their highly demanding role. By securing and supporting the role of the clinical nurse specialist nationally these nurses will be more able to advise and deliver many key service innovations which will enhance patients' experience of care and find new ways to meet their supportive care needs.

Information / Benchmarking

41. By 2015 it should be mandatory for the NHS to collect data on gynaecological (and other) cancers and for outcomes measures to be published at a national level for public scrutiny. Centres must be able to provide data on incidence of cancers, stage at diagnosis, histopathology, recurrence & survival data, treatments provided, complications & treatment-related morbidity, comorbitities 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.

42. 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.

43. The International Cancer Benchmarking Partnership will assess differences in the diagnosis and management practices of ovarian cancer in the United Kingdom in comparison with international partners. This data will help inform the development of services in the United Kingdom, working toward achieving outcomes data equivalent to the best jurisdictions in Europe and beyond.

44. The UKGOSOC audit of surgical outcomes and complications will produce a set of surgical complications data by 2011, and in collaboration with the National Cancer Intelligence Network (NCIN), the collaborators will work towards integrating this co-morbidity and surgical complications data into routine clinical practice. This process of integration of robust outcomes data capture into routine clinical will help to validate HES data and will provide additional data to demonstrate the quality of services. Integration into peer review will ensure that all centres embrace the process.

45. Once mechanisms for collecting and analysing benchmarking data are established, these data must become integrated into the peer review process.

46. As a guide 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.

47. Accruement and analysis of data regarding rare tumours (eg germ cell tumours) and uncommon / novel procedures (eg radical trachelectomy for cervical cancer) should be developed in association with the National Cancer Intelligence Network Gynaecology Clinical Reference Group, to enable specialist national audit, ensure consistent quality of care nationally and promote research.

48. Regular and rigorous patient surveys will assist in monitoring patients experiences, but will need to be backed up with more in-depth qualitative work on a local level.

<u>Research</u>

49. Clinical trials programmes should be coordinated across localities and ideally across wider areas. All centres and units must have adequate provision of clinical research nurse resources to facilitate trials recruitment, and this should be evidenced within the Peer Review process.

50. Integration of trials activity between the National Cancer Research Institute (NCRI), Cochrane and the BGCS will assist in trials development and improve recruitment.

51. More patients will be offered the opportunity to participate in clinical trials and will be supported in doing so.

52. Investment into how gynaecological cancers develop and how best to treat them should be prioritised in order to improve survival and quality of life for all those affected by these cancers.

Miscellaneous

53. 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 gynaeoncology.

Improving Outcomes: A Strategy for Cancer **Stakeholders**
December 2010