

Health and Social Care Committee Consultation on Gynaecological Cancers – closing 17th March 2023

Purpose of the consultation

The Health and Social Care Committee is looking at the experience of women with symptoms of gynaecological cancer, how they are listened to and treated by healthcare professionals, and how services empower, care for and look after women diagnosed with a gynaecological cancer (to ensure their physical, psychological and practical needs are met).

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The Gynaecological Cancer Site Group is a group of clinicians working within gynaecological cancer throughout Wales. The group welcomes anyone who has an interest in working within gynaecological cancer and improving the experiences and outcomes of women affected by cancer. I am grateful for the multiple conversations that I have had with many colleagues throughout Wales from within the Gynaecological CSG and the wider oncology community in preparation for this submission. We welcome this timely and important consultation, and the response is structured around the points listed on the consultation webpage. Where possible we have used published or unpublished data to support the evidence. Where data are lacking, we have drawn on personal experience and knowledge of the service.

1) The information available and awareness about the risk factors for gynaecological cancers across the life course and the symptoms associated with gynaecological cancers.

1.1 Gynaecological cancer can affect women of any age, and the term gynaecological cancer covers a complex array of different cancers within organs both outside and inside the body. The risk factors for the individual tumour sites vary. A variety of lifestyle factors contribute to gynaecological cancer, for examples smoking and obesity. Whilst many women are aware of the benefits of a healthy lifestyle, they may not be aware of the specific impact on gynaecological cancers. Patients who are diagnosed with gynaecological cancers frequently ask why they developed it. Genetic mutations can also lead to a greater risk of cancers and women might not be aware of this. In the Target Ovarian Cancer Pathfinder study of women in the general population in Wales, only 16% thought that genetics might be a factor in developing ovarian cancer.¹

1.2 The symptoms associated with gynaecological cancers are very varied and awareness of the symptoms appears to vary depending on the cancer site. For example, endometrial cancer typically presents with post-menopausal bleeding that alerts women to seek medical advice. As a result, women are frequently diagnosed with endometrial cancer at stage I, and have a good prognosis. In contrast, ovarian cancer is typically diagnosed at a late stage (stage III/IV). The symptoms of ovarian cancer are not symptoms that would be typically associated with the gynaecological tract. These include persistent bloating, early satiety

¹ Target Ovarian Cancer. (2016). Pathfinder Wales – transforming futures for women with ovarian cancer.

(feeling full quickly), loss of appetite, pelvic or abdominal pain, urinary urgency, changes in bowel habit, fatigue and weight loss. There is less awareness among women of these symptoms relating to gynaecological cancer. Evidence for this lack of awareness comes from the Target Ovarian Cancer Pathfinder Study of 2016 in Wales.² When women in the general population were asked to say which symptoms they think might be linked to ovarian cancer, only 18% were able to name pelvic or abdominal pain, 17% persistent bloating, 5% feeling full/loss of appetite and 1% increased urine urgency/frequency. A follow-on Pathfinder study was conducted and published in 2022, and although the results are reported for the UK, they also show low levels of awareness: 32% pelvic or abdominal pain; 21% persistent bloating; 3% feeling full/loss of appetite; 1% increased urinary frequency.³ Recent data from the Wales Macmillan Cancer Experience Survey shows that 24.9% of women waited three months or more from the time they first thought something was wrong with them until they first saw a GP or other doctor. 9.3% did not think something was wrong until they were told.⁴ Therefore women may not know the potential significance of the symptoms and this may delay their access to healthcare services.

1.3 Conversations with colleagues suggest that continued education is needed around particular issues such as: the upper limit of cervical screening (i.e. women still need cervical smears after the menopause); it is not only people with heterosexual contacts that develop cervical cancer; bloating/change of bowel habit is a symptom and not necessarily a sign of normal 'ageing'; gynaecological cancers can happen at any age, and the importance of internal examination where necessary; irritable bowel syndrome is an unusual first diagnosis for women in their 50's; hormone replacement therapy can mask symptoms of gynaecological cancer; education that a normal CA125 tumour marker does not exclude ovarian cancer. Initiatives such as Gateway C may increase awareness among healthcare professionals: Gateway C is a free educational resource that is available for Primary Care professionals across Wales that provides evidence based information to support early detection of cancer.

2) The barriers to securing a diagnosis, such as symptoms being dismissed or confused with other conditions.

2.1 There are many and varied barriers to women presenting to the Health Service. There is a lack of data to identify all the barriers within Wales or to quantify the number of individuals affected. Nevertheless, it is acknowledged that barriers include a past history of sexual assault, or conditions such as vaginismus (uncomfortable spasm in the vagina). Furthermore, women may be embarrassed. Other diverse groups of women for whom there may be a barrier to disclosing symptoms include those from ethnic minority groups, those living in areas of deprivation, members of the LGBTQ+ community, those with mental health issues, and those with learning difficulties or dementia.

2.2 Women report a variety of different experiences once they present with symptoms. Whilst some women are promptly referred for investigation, others report repeated visits to primary care before referral. Gynaecological specific data from the recent Wales Macmillan

² Target Ovarian Cancer. (2016). Pathfinder Wales – transforming futures for women with ovarian cancer.

³ Target Ovarian Cancer. (2022). Pathfinder 2022: Faster, further, and fairer

⁴ Wales Cancer Network, NHS Wales Health Collaborative personal communication. (2023).

Cancer Experience Survey show that whilst 50.5% of people with gynaecological cancer visited their GP only once before referral, 11.8% visited their GP on three or more occasions and 6.6% went straight to hospital via Accident and Emergency.⁵ For ovarian cancer, the Pathfinder Wales study found that 36% of women visited their GP three times or more before being referred for diagnostic tests, and 29% of women were initially referred for tests for something other than ovarian cancer.⁶ For cervical cancer, the NICE guidance on recognition and referral for suspected cancer states that if the appearance of the cervix is consistent with cervical cancer then this should trigger a referral for suspected cancer with an appointment within two weeks.⁷ Therefore, an examination is required to demonstrate the appearances of cancer, and there are reports of women not being examined. On occasion this is due to the lack of a chaperone in Primary Care. Whilst there has been an agreement during the pandemic that women can be referred without examination, these particular experiences relate to women being neither examined nor referred and they illustrate the importance of clinical examination.

3) Whether women feel they are being listened to by healthcare professionals and their symptoms taken seriously.

3.1 Among published reports it is also evident that there are a variety of experiences. The Macmillan Cancer Patient Experience Survey published in 2023 showed that 92% of people with cancer surveyed rated their cancer care in the first year of the pandemic as 7 or above out of 10, with 45% rating their care as very good or 10 out of 10.⁸ Although these data are not specific to people with gynaecological cancer, they correlate well with the Macmillan Wales Cancer Experience Survey of people with gynaecological cancer in Wales in 2013 where 87% of patients rated their overall NHS care as excellent or very good.⁹ Whilst many rate their care highly, there are undoubtedly women whose experience falls short. Free-text comments relating to gynaecological cancer from the recent Wales Macmillan Cancer Experience Survey provide examples of individual experiences.¹⁰ Whilst the survey was taken at a time where patient care was affected by the pandemic, the comments are of general relevance.

'Due to COVID I did not see my GP, but a telephone discussion resulted in my GP referring me straight to gynaecology, where a scan and taking a tissue sample was done in a timely period. The result was delivered within a week by a very caring Macmillan nurse, who gave me explanation on classification and type of cancer using a leaflet, which was useful as I was able to read up the information again later.'

'In a way, COVID-19 helped with my diagnosis and treatment. Within [number removed] days of seeing my GP I was having an ultrasound and CT scan and within [number removed] weeks I had had biopsies, aspiration of pleural effusions, had weekly telephone conversations with the gynaecologist and oncologist, face to face to discuss treatment then commenced chemotherapy.'

⁵ Wales Cancer Network, NHS Wales Health Collaborative personal communication. (2023).

⁶ Target Ovarian Cancer. (2016). Pathfinder Wales – transforming futures for women with ovarian cancer.

⁷ NICE. (2015). Suspected cancer: recognition and referral. NICE guideline [NG12]. Last updated: 15 December 2021.

⁸ Macmillan. (2023). Cancer Patient Experience Survey.

⁹ Macmillan. (2013). Macmillan Wales Cancer Patient Experience Programme 2013 National Survey.

¹⁰ Wales Cancer Network, NHS Wales Health Collaborative personal communication. (2023).

'I had a scan on [date removed] checked my organs which I didn't know was going to happen I suppose naive of me said all was ok but where [the healthcare professional] checked wasn't [where] my pain was. Doctor said they would refer me to Gynae but haven't hear anything yet.'

'I was meant to have surgery as we initially locked down. I quickly noticed something was very wrong and a big mass was growing in my abdomen. My GP wouldn't see me, my consultant wouldn't see me and when I presented at A and E, the gynaecology team dismissed me again. If I hadn't requested a CA125 blood test 5 months later, which showed an increase, I dread to think what could of happened to me.'

4) HPV vaccination and access to timely screening services including consideration of the inequalities and barriers that exist in uptake among different groups of women and girls.

4.1 Uptake for preventative measures such as HPV vaccination and screening vary among different groups in society such as those described previously in question 2. There may be cultural barriers that inhibit people from accessing HPV vaccination or screening. Parents may feel that HPV vaccination is not relevant or necessary for their children. Others may only visit healthcare services for a specific problem rather than for prevention.

4.2 For screening, as mentioned in question 2, women with a past history of sexual assault, mental health issues or conditions such as vaginismus may prevent them attending. Some would only accept screening if undertaken by a woman, and their fear that this might not be the case inhibits them from attending. Others may have difficulty attending for screening, for example due to their hours of work. Fear, embarrassment, lack of awareness and availability of the service are all factors.

4.3 On a positive note, introduction of primary screening for HPV is an excellent example of timely service development that can better direct follow up screening tests to those who need it most.

5) NHS recovery of screening and diagnostic services, specifically the level of extra capacity that has been provided for services to recover from the impact of the COVID-19 pandemic.

5.1 Colleagues around Wales report different experiences. Whilst some report that capacity is back to pre-pandemic levels, others report that the service has not recovered. Examples of the latter include a hysteroscopy clinic that was lost during the pandemic and not reinstated. This has caused additional pressure on other services within the Health Board. Others report loss of operating theatre capacity that has not recovered to pre-pandemic levels despite a post-covid increase in demand.

6) The prioritisation of pathways for gynaecological cancers as part of NHS recovery, including how gynaecological cancer waiting lists compare to other cancers and other specialities.

6.1 Gynaecological cancers are relatively uncommon compared with other tumour sites. For example there are around 2.5 times as many cases of breast cancer per year as there are gynaecological cancer. Gynaecological cancer is therefore a relatively small specialty. Gynaecological cancers are a diverse group of cancers which occur both inside and outside of the body. Within gynaecological cancer, there are five different tumour sites recognised by the National Institute of Health and Care Excellence (NICE).¹¹ Within these five tumour sites there are many different histological cell types that can occur. Therefore, gynaecological cancers are relatively uncommon, and many of them are rare. The presentations of gynaecological cancers are very different depending on the tumour site and, as such, each tumour site has a different pathway within gynaecological oncology. There are currently four Wales National Optimal Cancer Pathways for cervical, endometrial, ovarian and vulval cancer. So, within a relatively small specialty the service set-up is complex and there are many different routes to diagnosis. All patients need to be seen within a clinic – there isn't a diagnostic test that can be performed to rule out a cancer in advance of a clinic appointment. Within a gynaecological department, patients may be referred to, for example, a post-menopausal bleeding (PMB) clinic, a colposcopy clinic, an urgent suspected cancer clinic or a pelvic mass clinic. These 'entry points' lead to very different cancer pathways. Some of the services are one-stop services including a biopsy and radiology, and there are examples of pilots of other novel routes of entry such as a one-stop ovarian cancer service. There is a need to evaluate these new models further and to see if they can improve compliance with the single pathway and early diagnosis.

6.2 The NHS Wales Cancer dashboard currently shows waiting times for gynaecological cancer are long, with low percentages of women starting treatment within 62 days of the first suspicion. Clinicians working in sites where capacity has not returned to pre-pandemic levels report difficulties reinstating services. Capacity issues are very real within gynaecological cancer services. This involves gynaecological-specific services such as a gynaecological rapid assessment service, or services that work across tumour sites such as radiology and pathology. There are theatre capacity issues and pressure on services such as radiotherapy and systemic anti-cancer chemotherapy (SACT). Capacity issues involve both the facilities and the workforce, and workforce issues are not easy to fix rapidly as recruitment and training is required. There are reports of very large numbers of referrals requiring triage. Long waiting times in non-urgent services mean that patients are more likely to be referred on an urgent suspected cancer pathway because of concerns waiting for routine appointments. Within the pathways, delays occur in obtaining radiological tests, biopsies and pathological reporting.

6.3 Gynaecological cancer pathways are frequently complex. Due to gynaecological cancers being relatively uncommon, much of the treatments are delivered in cancer centres, whilst patients present initially to cancer units. Colleagues describe occasions where patients see a general gynaecologist and then need to see the cancer unit lead gynaecologist. Patients are then further referred to a gynae-oncologist in the cancer centre which may be in a different Health Board. This requires discussion in the local multi-disciplinary team meeting (MDT) and then the cancer centre MDT. Although there are examples of collaborative working such as a gynae-oncologist from a cancer centre holding clinics in a cancer unit,

¹¹ NICE. (2015). Suspected cancer: recognition and referral. NICE guideline [NG12]. Last updated: 15 December 2021.

there is a lack of regional commissioning that would facilitate better use of resources and smooth out inconsistencies.

6.4 For radiology, there are delays in obtaining scans as well as delays in reporting scans. There is a shortage of radiologists. The Royal College of Radiologists Clinical Radiology census, 2020 showed significant variability across the UK in the distribution of clinical radiology consultants relative to population size.¹² Wales has the lowest number of clinical radiologists per head of population within the UK (7.8 per 100,000 compared with a UK average of 8.6). This compares with the European average of 12.8 radiologists per 100,000 population. Compared to France and Spain, Wales has half the number of radiologists per head of population. Ten percent of clinical radiology consultant posts in Wales were vacant in 2020. Delays in reporting lead to delays in MDT discussions which contributes to longer waiting times.

6.5 Within pathology, there are vacancies within Wales. The Royal College of Pathologists workforce census in 2018 showed that 17% of consultant pathologists in Wales are locums.¹³ Wales had the highest proportion of staff aged 55 or more, at 36%, with 12% at least 60 – the highest of the four UK nations. Workforce shortages lead to delays in reporting histopathological specimens. In addition, specimens frequently need to be reviewed in the cancer centre MDT. Although digital solutions are being explored and piloted, the specimens currently need to be sent to the cancer centre health board, and this can incur further delays.

6.6 Within gynae-oncology surgical services and oncology services there are also workforce issues within a range of professional groups. Because the teams are generally made up of small numbers of clinicians there is a large impact of vacancies and absences from work. Some colleagues are working as single-handed consultants meaning that the service is lacking in resilience. There is inequity of access to gynaecological cancer clinical nurse specialists.

6.7 Waiting times for cancer diagnosis and treatment are therefore reliant on relatively small teams in multiple locations, managing multiple and varied clinical pathways, for often uncommon or rare cancers, and coordinating among health boards. Pathways require infrastructure (clinic provision, theatre space) and a multi-professional workforce (including gynaecology, gynae-oncology, pathology, radiology, oncology, cancer nurse specialists and MDT coordinators). Small teams are more vulnerable when there are staff vacancies or members of the team are away. If a single member of a team of two is away, then the workload doubles for the remaining individual and the capacity of the service may be halved. If a single-handed practitioner is away, then the service stops. The pathways need resilience both within gynaecological cancer teams and in the wider NHS.

7) Whether there are local disparities in gynaecological cancer backlogs (addressing inequalities so that access to gynaecological cancer care and treatment is not dependent on where women live).

¹² RCR. (2021). Clinical radiology UK workforce census 2020 report. London: The Royal College of Radiologists.

¹³ RCPATH. (2018). Meeting pathology demand. Histopathology workforce census. London: The Royal College of Pathologists.

7.1 Within General Practice, there may be difficulties accessing a female GP, particularly in rural communities. As mentioned there are some areas where capacity has not recovered from the pandemic. Data from StatsWales reveal a dynamic picture with local disparities among health boards with regard to waiting times. There are also reports of different waits within individual health boards, dependent on local services.

8) The extent to which data is disaggregated by cancer type (as opposed to pooling all gynaecological cancers together) and by other characteristics such as ethnicity.

8.1 Routinely available data on an All-Wales basis is not disaggregated by cancer type, and all gynaecological cancers are pooled together.

8.2 For example women with endometrial cancer typically present with post-menopausal bleeding (PMB) and would be referred to a 'PMB clinic'. In contrast women who are suspected of having cervical cancer might be referred to a colposcopy clinic. Women with suspected ovarian cancer might be referred to an urgent suspected cancer clinic or to a non-gynaecological specialty. Due to gynaecological cancers being relatively uncommon, gynaecological cancer teams are generally small teams who need to manage all these different pathways. Receiving data pooled together as gynaecological cancers makes it difficult or impossible to provide robust evidence of where the pinch-points are in the various cancer pathways. Providing cancer performance teams in each health board with the same coding for individual gynaecological cancer types for tracking purposes would allow a focussed approach with each cancer pathway. Automated data collection systems improve efficiency and compliance.

9) Whether adequate priority is given to gynaecological cancers in the forthcoming Welsh Government/NHS Wales action plans on women and girls' health and cancer, including details of who is responsible for the leadership and innovation needed to improve cancer survival rates for women.

9.1 We are aware of the Planned Care Programme for gynaecology being transferred from a Welsh Government driven programme to an NHS programme driven by the Planned Care Improvement and Recovery team. This is currently being relaunched.

9.2 For the recently published Women's Health in Wales Discovery Report, there isn't a specific section on cancer, however many aspects of the report are relevant to cancer, not least healthy lifestyle choices, access to healthcare, information, education and communication, and research.¹⁴ Within the document, public health considerations including screening are listed as a priority area. Leadership is not specifically mentioned. The document references the Healthier Wales Women and Girls survey. The reported age profile of the respondents showed that 9.2% of respondents were aged 65 or over, compared with national statistics where 22.5% are in this age group. This contrasts with the age profile of those responding to the recent Macmillan Cancer Experience Survey Results where 59% of those with gynaecological tumours were aged 65 or over, reflecting the fact

¹⁴ NHS Wales. (2022). Women's health in Wales. A Discovery report: foundations for a women's health plan.

that the incidence of cancer rises with increasing age. Nevertheless, gynaecological cancers affect women of all ages, and focus groups within the survey highlighted areas that are of great relevance to cancer including access to services, informed choices, embarrassment and shame, research, listening.

9.3 The Wales Cancer Network three-year Cancer Improvement Plan focusses on improving cancer services, experience and outcomes.¹⁵ This is a generic document but of great relevance to gynaecological cancer.

9.4 Within Wales we feel that leadership is multifactorial. Leadership occurs at many levels including government, health boards, cancer services and MDTs.

9.5 Within the Wales Cancer Network, there are tumour site specific Cancer Site Groups (CSGs). These are advisory groups with no direct managerial responsibility. Engagement with the CSG is voluntary and clinicians that make up the groups are not remunerated. The gynaecological CSG is active and engaged. Within the gynaecological CSG, there have been a number of initiatives and projects in recent years. These include:

- Members of the gynaecological CSG have developed four National Optimal Pathways for cancer diagnosis in ovarian, endometrial, cervical and vulval cancers.
- Development of all-Wales guidelines for cervical cancer, ovarian, fallopian tube and primary peritoneal cancer, uterine cancer, vulval cancer, testing for Lynch syndrome, and gynaecological cancer follow up.
- Members of the gynaecological CSG have successfully developed and put forward the clinical case introducing PET scanning within gynaecological cancer in Wales. This includes written submissions to the Welsh Health Specialised Services Committee.
- The gynaecological CSG has undertaken national peer review, which has highlighted inequities including the need for acute oncology services and Cancer Nurse Specialists. This has undoubtedly supported health boards to develop business cases and services development.
- The gynaecological CSG has provided clinical leadership to work alongside the clinical and laboratory Genetics services to develop pathways for clinician-led BRCA testing and, more recently, testing for homologous recombination deficiency (HDR). Similarly, pathways for mis-match repair (MMR), promotor methylation testing (for Lynch syndrome), and genetic POLE testing, which is required for molecular classification of endometrial cancer, have been developed by collaborative working between the gynaecological CSG and colleagues in Genetics. This has included the development and delivery on-line education sessions, supported by the Wales Cancer Network. These tests are important for identifying people at increased risk of cancer and for informing treatment decisions for patients with cancer, including the use of new drugs that are approved by the National Institute for Health and Care Excellence (NICE). These excellent collaborations with colleagues in Genetics mean that Wales is among the of earliest regions to take innovations in genetics into clinical practice.
- The gynaecological CSG holds an annual all-Wales educational event. Although paused during the pandemic, it was reinstated in 2022. These events include

¹⁵ Wales Cancer Network. (2023). A cancer improvement plan for NHS Wales 2023-2026.

internationally renowned speakers and provide updates on innovations in gynaecological cancer, sharing of best practice and networking opportunities.

- Gynaecological CSG members have also provided clinical leadership for successful applications for the use of bevacizumab in Wales for ovarian and cervical cancer, thus enhancing equity of access with other UK nations.
- Clinical representation on the International Cancer Benchmarking Partnership ensures Wales is represented internationally.
- With administrative support from the Network, colleagues within the gynaecological CSG have championed the need for a national ovarian cancer audit, and have done background work on what information is available via existing databases and the logistics of collecting data. This has led to an extensive data collection study. These foundations have helped to highlight the need for a national audit and has put us on a firm foundation now that the planned Health Quality Improvement Partnership (HQIP) ovarian cancer audit has been announced.
- The Gynaecological CSG facilitated and supported a successful application to the Ovarian Cancer Action Improve UK initiative for the All Wales Ovarian Cancer Prehabilitation Programme. This involved interventions from dieticians, occupational therapists, physiotherapists, geriatricians and prehab nurses. The results have reduced hospital stay and interval from surgery to chemotherapy compared with historical data.

10) The extent to which gynaecological cancers, and their causes and treatments (including side-effects), are under-researched; and the action needed to speed up health research and medical breakthroughs in diagnosing and treating gynaecological cancers.

10.1 Further research is needed within gynaecological cancer. Within Wales there is research taking place within Universities and the clinical service. Wales has representatives within research at national and international levels within the UK National Cancer Research Institute and the International Cancer Benchmarking Partnership.

10.2 As is the case with all cancer, many research questions remain unanswered and much more research is required to improve the lives of women diagnosed with these cancers. There is however growing academic interest and activity in Wales. The Wales Cancer Research Centre gynaecology oncology multidisciplinary research group (MDRG) formed in 2021 has mapped out the research activity in Wales and brought healthcare professionals and scientists together to network, develop new ideas, promote existing research and problem solve. This group links with the Wales Cancer Network Gynaecology Cancer Subgroup (CSG) so that all relevant stakeholders are aware of research activities and ideas creating a bidirectional flow of information with the aim of developing meaningful research in the context of Welsh gynaecological cancer care.

10.3 To give a few examples of the excellent work we have going on, we have scientists in Wales undertaking basic science research investigating prognostic and predictive biomarkers in patients with ovarian cancer. This work requires collaborative working for successful sample collection between clinicians and scientists at several sites in Wales and is growing in success as time goes on. We have scientists developing state-of-the-art,

advanced therapies such as virotherapies and nanomedicines in the context of gynaecological cancers which have the potential to have significant positive impact on patient prognosis. Some of these therapies are approaching first in human stage of development. We have psychologists carrying out qualitative research to better understand why patients don't engage with cervical screening and prehabilitation. We have clinicians leading collaborative research investigating novel therapies and biomarkers that can be used in the treatment of vulval intraepithelial neoplasias and undertaking patient surveys evaluating patient experience of vulval services in general. We have clinicians in Wales leading UK teams running multicentre randomised controlled trials investigating novel therapies in patients with gynaecological cancer and including the associated translational research and much more. There is a definite enthusiasm and willingness in Wales to grow research and put Wales on the map for the benefit of our patients. The MDRG has aided in this.

10.4 Despite this much more could be done. Very few healthcare professionals in gynaecological cancer have research time in their job plans and are commonly not appropriately remunerated for research work they carry out. To encourage clinicians to open existing clinical trial in their centres appropriate remuneration for the work this requires should be made. This would motivate more clinicians to carry out principle investigator (PI) work and increase the access Welsh patients have to clinical trials. This can be demoralising for staff and lead to lack of engagement. Research fellowships are relatively few in number in Wales (although increasing in number over recent years). More support and funding to run fellowships would engage clinicians early in their training and encourage more Welsh trained consultants to continue with academia in their consultant posts. Further, national audit and service evaluation needs to be undertaken to allow us to establish deficiencies in our services and identify areas of research that should be focused on in Wales to focus some research on tackling these issues and raising the standard of care offered.

10.5 For clinical research, colleagues report vacancies within clinical trials units and a lengthy process to set up clinical trials. Some specialised clinical trials are open in selected centres and there are reports of practical and funding difficulties referring patients to clinical trials in England if those trials are not available in Wales.

10.6 For side effects of treatment, an example is the late effects of pelvic radiotherapy. This is an area of unmet need that requires the identification, investigation and treatment of patients with side effects, sometimes years after treatment, and after patients have been discharged from follow-up. There is variation of provision of a late effects service among health boards.

10.7 There is a need for more and accurate data on gynaecological cancer within Wales. This includes data on waiting times, disaggregated for tumour type and with more granular detail of the pathways. Currently data are available by health board and divided into whether patients are waiting for diagnostics or treatment, but there is no other detail available to drill down to which diagnostic test or which treatment is awaited, and where the issues lie. Clinicians are often reliant on reporting their own experiences without data to back up their assumptions. More detailed data currently require individual service

reviews or audits with manual collection of data which is very time-consuming. There is a need for accurate, automated data entry and data collection on waiting times, treatments delivered, and outcomes (e.g. local control, survival, toxicity) and patient reported outcome measures. This requires accurate coding, computer systems to handle large amounts of data and the ability to interpret the outcomes. Organisational and management structures are required to translate insights and innovations into clinical practice.

11) The priority given to planning for new innovations (therapy, drugs, tests) that can improve outcomes and survival rates for women.

11.1 New NICE-approved drugs are currently made available in Wales, with funding for the drugs themselves. However there is an impact on the service when new treatments are introduced, especially if these are maintenance treatments where patients will be on therapy for two years or more. Funding is also required for pharmacy to prepare the drugs, chair time (if the drug is given intravenously), prescribing and out-patient review and management of toxicities. With new indications becoming available, additional strain is put onto the capacity to deliver treatments. Once the service has flexed beyond its existing capacity, new staff appointments and infrastructure are required. The infrastructure needs to support local and regional services, joined up working, collaboration for the clinical service and research, and sharing of best practice. This is the best way to ensure equity of access of treatments for patients.

11.2 The provision of some new treatments and innovations have taken longer than in some other UK nations. Examples include bevacizumab in ovarian and cervical cancer. The provision of new innovations not only benefits patients, but also has the potential to enhance the workforce recruitment by making jobs attractive within Wales. For data collection, a pilot national ovarian cancer audit took place in England. Unfortunately it wasn't possible for Wales to take part in this because of the lack of a funding stream and compatibility of computer systems. A baseline audit did take place in Wales but required individual patient data collection. Pleasingly Wales will now be taking part in the forthcoming HQIP audit. In addition to new innovations on therapy, drugs and tests, there is a need efficient and accurate data collection to facilitate the evaluation of these advances.

11.3 Other innovations have been adopted rapidly into clinical services within Wales. Examples include developments in genetic testing such as increased capacity for BRCA testing, HRD testing and POLE testing.