

## **Agenda – Health and Social Care Committee**

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Meeting Venue:	For further information contact:
Hybrid – Committee room 5 Tŷ Hywel and video conference via Zoom	Sarah Beasley Committee Clerk
Meeting date: 21 September 2023	0300 200 6565
Meeting time: 09.30	<a href="mailto:SeneddHealth@senedd.wales">SeneddHealth@senedd.wales</a>

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### **Private pre-meeting (09.00–09.30)**

- 1 Introductions, apologies, substitutions, and declarations of interest**  
(09.30)
  - 2 Gynaecological cancers: evidence session with the Minister for Health and Social Services**  
(09.30–10.45) (Pages 1 – 66)  
Eluned Morgan MS, Minister for Health and Social Services  
Professor Chris Jones – Deputy Chief Medical Officer – Welsh Government  
Nick Wood – Deputy Chief Executive NHS Wales – Welsh Government  
  
Research brief  
Paper 1 – Welsh Government  
Paper 2 – Gynaecological cancers engagement findings
  - 3 Motion under Standing Order 17.42 (ix) to resolve to exclude the public for items 4, 7, 8 and 9**  
(10.45)
  - 4 Gynaecological cancers: consideration of evidence**  
(10:45–11:15)
- Break (11.15 – 11.30)**

- 5 European models of health and social care: evidence session with academics**  
(11.30–12.45) (Pages 67 – 74)  
Research brief  
Mark Dayan, Policy Analyst and Head of Public Affairs, Trade and Brexit programme lead – Nuffield Trust  
Professor Scott L Greer, Professor of Health Management and Policy and Global Public Health, University of Michigan, and Senior Expert Advisor on Health Governance to the European Observatory on Health Systems and Policies
- 6 Papers to note**  
(12.45)
- 7 European models of health and social care: consideration of evidence**  
(12:45–13:00)
- 8 Supporting people with chronic conditions: approach to phase 2**  
(13:00–13:15) (Pages 75 – 81)  
Paper 3 – Scoping paper: phase 2 of supporting people with chronic conditions
- 9 Forward work programme**  
(13.15–13.30) (Pages 82 – 93)  
Paper 4 – Forward work programme

Document is Restricted

## Committee Inquiry into Gynaecological Cancer: evidence from the Minister for Health and Social Services

### Gynaecological Cancer

The NHS classifies cases of cancer by main cancer type, often determined by the part of the body affected and the medical specialty that typically oversees the treatment. Gynaecological cancer includes several organ specific sub-types, such as cervical, ovarian (including fallopian tube and primary peritoneal), uterine (including endometrial and sarcoma), vulval, and vaginal. Some cases of gynaecological cancer can present where the origin of the original cancer cannot be determined.

The Wales Cancer Intelligence and Surveillance Unit at Public Health Wales (PHW) is responsible for publishing official statistics on cancer incidence and survival. The most recent data, for the period 2017-2019 indicates roughly 1,030 people are diagnosed in each year with either cervical, ovarian, or uterine cancer. The number of cases and incidence rate per 100,000 people for both cervical and ovarian cancer has fallen between 2002-04 and 2017-19; but has increased for cancer of the uterus. Figures for vulval and vaginal cancer from Cancer Research UK indicate there were 76 cases of vulval cancer and 13 cases of vaginal cancer in Wales between 2016-18.

	Count of cases		Crude rate per 100,000 people		Age adjusted rate per 100,000 people (with 95% confidence intervals)	
	2002-04	2017-19	2002-04	2017-19	2002-04	2017-19
<b>Cervical</b>	492	477	10.84	9.99	11.14 (10.17-12.17)	10.40 (9.48-11.38)
<b>Ovarian</b>	1189	973	26.2	20.38	26.65 (25.15-28.22)	19.12 (17.93-20.37)
<b>Uterine</b>	1058	1641	23.32	34.37	23.90 (22.47-25.4)	31.86 (30.33-33.45)

Source: [Cancer Incidence in Wales, 2002-2019 - Public Health Wales \(nhs.wales\)](https://nhs.uk/publications/cancer-incidence-in-wales-2002-2019)

Survival and mortality rates have improved for both cervical and ovarian cancer but may have deteriorated for cancer of the uterus. It is important to note that some of the difference in these figures demonstrate no statistical significance as the confidence intervals of the two figures overlap.

	Age standardised mortality rate per 100,000 people (with 95% confidence intervals)		Five Year Net Survival (with 95% confidence intervals)	
	2002-04	2019-21	2002-06	2015-19
<b>Cervical</b>	4.07 (3.5-4.71)	2.85 (2.4-3.37)	61.98% (58.30-65.66)	73.25% (69.65-76.84)
<b>Ovarian</b>	15.48 (14.34-16.68)	11.82 (10.92-12.78)	37.89% (35.33-40.45)	46.49% (43.38-49.61)
<b>Uterine</b>	4.09 (3.52-4.72)	7.11 (6.42-7.85)	77.32% (74.54-80.10)	76.17% (73.73-78.60)

Source: [Welsh Cancer Intelligence and Surveillance Unit \(WCISU\) - Public Health Wales \(nhs.wales\)](https://nhs.uk/publications/welsh-cancer-intelligence-and-surveillance-unit-wcisu)

In terms of patient reported experience, the most recent Wales Cancer Patient Experience Survey (2020-21) demonstrated that respondents with gynaecological

cancer rated their care highly, with an average 8.5 out of 10; although this was slightly below the survey average for all cancers included (8.7).

### **Presentation and referral for suspected cancer**

The National Institute for Health and Care Excellence sets out the referral criteria that clinicians apply when considering risk factors and symptoms for suspected cancer. These criteria have a positive predictive value for cancer as low as 3%. In other words, the risk factors and symptoms used to identify somebody at risk of gynaecological cancer have a very low likelihood, at population level, of resulting in a diagnosis of cancer. National data suggests that of all those referred with suspected gynaecological cancer, around 5% (or less in some health boards) of referred cases will convert to a confirmed diagnosis.

The vast majority of people presenting and referred will not have gynaecological cancer, but the NHS will still need to investigate and report on these patients referred with suspected cancer within the 62-day cancer pathway. For every single gynaecological cancer patient requiring treatment within the waiting time, the NHS will have investigated nearly 20 times that number in order to rule out gynaecological cancer. The number of people that need to be investigated based on risk and symptoms therefore poses significant challenges for the available diagnostic capacity. However, we must recognise the importance of providing timely reassurance to people referred with suspected cancer that they do not have a confirmed cancer.

The referral guidance is also complex and detailed, posing challenges for raising and sustaining public awareness beyond obvious red flag symptoms such as post-menopausal bleeding among women over the age of 55:

[Recommendations organised by site of cancer | Suspected cancer: recognition and referral | Guidance | NICE](#)

The referral criteria are different for different sub-types of gynaecological cancer and often the symptoms bear little obvious relation to the possible existence of gynaecological cancers. These symptoms can be very common and difficult to identify, and normally have much less serious causes. Such symptoms include loss of appetite, increased urination frequency, and the feeling of bloating. It is very challenging for clinicians such as General Practitioners to apply these guidelines in real world situations, where patients present with complicated medical histories and given the relative risk of serious underlying illness. GPs must exercise their clinical judgement, using national guidelines, to manage risk and when appropriate make referrals for suspected cancer.

Nonetheless, there are clear and well-established evidence-based guidelines for referring clinicians to follow and we expect these to be routinely applied in Wales. In order to support GPs with these difficult assessments, the NHS in Wales is rolling out a digital support aid called GatewayC. This will support GPs to assess people presenting with symptoms and risk factors that should result in a suspected cancer referral. Since the NICE referral guideline was introduced in 2015, the number of suspected cancer referrals has more than doubled in Wales, which demonstrates

that GPs' willingness to refer people for investigation has increased. In addition, Wales has made significant progress in establishing Rapid Diagnostic Centres, with eight across Wales and the whole population covered. These give GPs an additional referral option for cases where they suspect cancer, but the person's symptoms do not meet the official referral criteria. A small number of cases of gynaecological cancer have been identified through this route.

### **Gynaecological Cancer Services**

Once a person is referred with suspected gynaecological cancer, they will typically be referred to a gynaecology outpatient clinic for assessment. These are delivered by all health boards except Powys, where patients are referred to neighbouring NHS organisations. Alternative routes to diagnosis include those people identified in the emergency department, those who are identified as an incidental finding when receiving healthcare for another reason, as well as those coming through the cervical cancer screening programme.

Depending on the referring symptoms and the type of suspected cancer, a woman may receive a diagnostic procedure such as an ultrasound, colposcopy, or hysteroscopy, often at the same first outpatient appointment. Some health boards arrange their outpatient clinics according to the referring symptom, in recognition that these referrals should be dealt with quickly and require similar investigations. Stratifying service provision in this way allows health boards to deliver more efficient services. For example, some health boards have dedicated post-menopausal bleeding clinics for the rapid investigation of suspected uterine cancer.

Patients are likely to receive a biopsy by the local gynaecology service and any staging investigations such as an MRI scan. Local Multi-Disciplinary Teams and regional Multi-Disciplinary Teams will support lead clinicians to guide treatment decisions. While patients with low-risk endometrial cancer receive a hysterectomy at their local health board, most surgical care will be provided in the regional gynaecological cancer centre, requiring referral from the person's health board of residence. Similarly, patients requiring chemotherapy and/or radiotherapy as a first definitive or adjuvant treatment will need to be referred to one of the three regional cancer centres in Wales (or for some Powys patients, to providers in England). However, follow up care will often be provided locally in the person's health board of residence.

These patient pathways vary depending on the cancer sub-type, sub-classification, and disease progression. For instance, patients with higher risk uterine cancer will receive surgery in the regional centre and subject to risk may also receive adjuvant chemotherapy, external beam radiotherapy and/or brachytherapy. Patients with ovarian cancer without significant evidence of distant spread undergo primary surgery in the regional centre and most patients undergo postoperative adjuvant chemotherapy. Whereas patients whose CT scan shows evidence of disease spread often have a diagnostic biopsy first, followed by chemotherapy as first definitive treatment. Some patients will then have debulking surgery and then additional chemotherapy, and some patients will benefit from long-term maintenance treatment. Similarly, patients with early-stage cervical cancer are treated surgically at the regional centre but a smaller proportion will also need adjuvant chemoradiotherapy.

Whereas patients with locally advanced disease may require PET-CT scan and may receive chemoradiotherapy (potentially including brachytherapy) as first definitive treatment.

Relative to other types of cancer, gynaecological cancers represent approximately 11% of pathways opened on the suspected cancer pathway. In treatment terms, it represents approximately 12% of people typically waiting on the suspected cancer pathway and 5% of those being treated in any given month. Although gynaecological cancer does not represent a large proportion of cancer cases, the cancer waiting time performance is one of the most challenged. Cancer performance over the most recent 12-month period for gynaecological cancer was 34.2%, compared to 55.1% for all cancers.

<b>Closed (completed) pathways for gynaecological cancer</b>			<b>Open (uncompleted) pathways</b>	
[Official statistics]			[Management data. Source: NHS Executive. This data is unvalidated and is provided as an indication only]	
12-month performance (Jun-22 to May-23)	Number treated (Jun-22 to May-23)	Number informed they do not have cancer (Jun-22 to May-23)	Overall waiting list (as at 13/8/23)	62-day breaches (as at 13/8/23)
34.2%	1,009	18,286	2,765	453

There is also variation by health board that reflects local service capacity, service models, and workforce constraints.

<b>12-month cancer performance by health board for gynaecological cancer</b>						
[Official statistics]						
(Jun-22 to May-23)						
Aneurin Bevan	Cardiff and Vale	Cwm Taff Morgannwg	Swansea Bay	Hywel Dda	Powys	Betsi Cadwaladr
28.2%	40.2%	27.3%	29.9%	25.8%	N/A	50.7%

As the population ages, we expect to see more cases of cancer over the long-term, and this may be further exacerbated by population rates of obesity and historic patterns of smoking. This increase was seen for uterine cancer up to 2019 but the number and rate of confirmed cases of cervical and ovarian cancers were falling up to 2019. In the case of cervical cancer this may in part be caused by the impact of the cervical screening and HPV vaccination programmes.

It is important to note that NHS activity data is more up to date than official statistics of cancer incidence but as the data is unvalidated, it is only an indication of the true picture. The number of patients starting suspected gynaecological cancer pathways in the 12-months to May-23 increased significantly compared to the 12-months to May-22. This more recent NHS activity data shows a large increase in referrals for

suspect gynaecological cancer, but we do not yet have official statistics for the same period to determine if there are in fact more confirmed cases. We also cannot break down the referral data by cancer sub-type, so we cannot confirm which types of gynaecological cancer may be contributing most to those increases.

However, we can see that as the number of people referred has increased, the proportion that convert to a cancer diagnosis has decreased, and the number starting treatment has actually fallen. The number of patients starting treatment in the 12-months to May-23 (1,017) has decreased by 6% compared to the 12-months to May-22 (1,082). The number being starting treatment should not be confused with the number of new cases, as the number of people requiring investigation impacts the capacity to start treatment. If there are many more people requiring investigation, the vast majority of which do not have cancer, then this impacts the capacity within the pathway to commence treatment for those that do. Unvalidated management data indicates that the number of patients actively waiting at diagnostic stage of the pathway has increased by 30% in the last twelve months (as at 13/08/2023). With many patients waiting for hysteroscopy.

The increase in gynaecological cancer referrals may also relate to the distorting impact on patient and clinical behaviour of the pandemic. Patients may have delayed presenting with vague symptoms of concern during the first years of the pandemic and may now be coming forward. In addition, the recovery of more normal service models may be a contributing factor. We may not have a clear picture of the period 2020-2023 for several years, as official statistics on cancer incidence and stage at diagnosis emerges.

In terms of the NHS ability to recover cancer performance, while gynaecological cancer is not relatively large in terms of patient numbers, the pathway is characterised by a high degree of complexity, inter-organisational referrals, a smaller more limited specialist workforce, the recent introduction of new genomic testing requirements, and the wider challenges in diagnostic service capacity facing all cancer types. Health boards have also been focusing on those patients that have already waited longer than the 62-day pathway target and this will impact reported performance. In addition, the single cancer pathway is a much more accurate measure of performance, capturing more patients in the system, starting earlier in the patient journey, and eradicating pauses to the waiting time clock.

## **Cancer policy**

The Welsh Government set out its approach to improving cancer outcomes in the Quality Statement for Cancer in March 2021:

[The quality statement for cancer \[HTML\] | GOV.WALES](#)

It was the first such document developed in response to the commitment made in *A Healthier Wales* to introduce quality statements to support the planning and accountability arrangements used by the NHS in Wales. The Quality Statement sets out what good cancer services look like in the form of commissioning statements. It also includes a number of nationally agreed pathways of care for different types of cancer, setting out what a patient should receive between presentation and start of



first definitive treatment. These pathways provide guidance for health boards and trusts to plan, organise, monitor, and improve local services according to a common standard that will deliver the cancer waiting time target. Health boards, trusts and special health authorities need to respond to these expectations and apply the national pathways through their local planning processes. Subsequently, the Welsh Government-led, formal accountability processes for the NHS in Wales monitor and challenge service planning and delivery in line with these expectations and pathways.

This approach is designed to work within how the NHS in Wales is organised, funded, delivered, and held to account. It recognises that improvement is likely to be iterative and requires sustained focus through accountability arrangements. This ongoing process is supported by the NHS Executive, which brings together clinical, programme, data, and improvement specialists to support improvement in NHS service quality. As a result the NHS in Wales has collaborated to develop, publish, and begin implementing 21 nationally agreed pathways, including four pathways for gynaecological cancers: cervical, uterine (endometrial), ovarian, and vulval. These pathways can be found at: [Suspected Cancer Pathway - NHS Wales Executive](#)

The NHS in Wales has also collaborated to develop a national response to the Quality Statement. The Cancer Improvement Plan for Wales, published in January 2023, set out how the NHS will respond. This includes a number of pertinent actions that will support improved gynaecological cancer care, such as the development of screening services, the introduction of prehabilitation, improved diagnostic services, recovery of waiting times, and transformation in service models.

The Quality Statement also sets the expectation that 75% of people referred on the suspected cancer pathway start definitive treatment within 62 days of their point of suspicion. This applies to gynaecological cancer as a general planning principle but does not override local clinical decision making with regard to clinical urgency. It is important to recognise that this is a 'closed' pathway measure reported monthly. It is the percentage of people that started treatment or were discharged from the pathway without gynaecological cancer. It does not report or measure the waiting time of those who are yet to start treatment or are yet to be discharged without gynaecological cancer (so called 'open' pathways).

### **Welsh Government Oversight**

The Welsh Government has put in place an enhanced escalation approach for cancer services in response to the Transforming and Modernising Planned Care Plan, as well as my concerns over the past 18 months about the pace of recovery in cancer services. This has a number of parts, including enhanced planning focus on health board recovery trajectories, routine scrutiny of health board recovery profiles through accountability forums (Integrated Quality Planning and Delivery meetings, and Joint Executive Team meetings) held individually with each organisation. In addition, the Welsh Government performance and escalation team – with support from the NHS Executive – is having monthly meetings with each health board specifically on their cancer performance. Cancer performance is also a factor in the escalation status of a number of health boards and therefore subject to the enhanced monitoring arrangements involved in the escalation framework.

I have made cancer one of my six priorities in the NHS planning framework and held two national summits of cancer service leaders in the past twelve months to ensure the NHS as a system is giving cancer sufficient focus. At the most recent summit in March I requested an enhanced focus on three cancer types, one of which is gynaecological cancer. In support of this, the NHS Executive is introducing a new national intervention to support local organisations to improve in these priority areas. This involves support from the national advisers and leaders in the Executive and embedded staff in local organisations helping teams to apply the four gynaecological cancer pathways that have been agreed nationally. I expect to see improvement in this service over the coming year.

This effort relates back to my expectations in the Quality Statement, that:

- the NHS start definitive treatment within 62 days of the point of suspicion for 75% of patients.
- the NHS adopts the nationally optimised pathways.
- we have an immediate system-wide focus on recovery from the impact of the pandemic.
- more cases are detected at earlier stages and people have access to evidence-based therapies.
- enhanced local planning arrangement and national support through the NHS Executive.

All these areas are currently subject to the required work and focus to improve services and outcomes for patients. There are a number of areas where we are looking to make specific progress of interest to the Committee. One of these is data. We have made very large progress in Wales in overhauling our data and reporting systems. The Cancer Network Information System Cymru, which captures most cancer data, is being phased out and replaced with a modern integrated healthcare record available across the whole of Wales and visible to all specialties. This will make a step change in what data can and should be captured.

It has allowed us to bring up to date what data are being included, ensure it is comparable across Wales, and flows in an automated and more timely way through to our reporting systems. In tandem, we have been improving health board business intelligence software that is used to track patients and manage local cancer pathways. One of the next phases in this work is to look at producing data and reporting at cancer sub-type level, for instance ovarian or uterine. There is some more work to do to make sure we have common definitions across Wales, and I would caution that data on referrals won't have a confirmed cancer sub-type, but we need to be able to at least report closed pathway data by sub-type.

More importantly, we're looking to get much more detailed cancer-specific data on the diagnostic parts of the pathway, so we can really see what stages of the pathway are causing the most delay and then target them. Some of the emerging data suggests that radiology is the largest contributor to pathway delays, particularly MRI reporting. We also want to improve data on route to diagnosis and stage at diagnosis to enable us to target interventions to achieve earlier diagnosis. More broadly, on the point about patient demographic information, such as ethnicity, the NHS Health

Inequalities Group has a subgroup for data, and will be looking at how we can improve data capture for all conditions as part of the patient's core record. This is not a matter limited to cancer care and it needs to be resolved for all conditions.

Finally, I would also like to reference the extension of the clinical audit programme over the next few years to include ovarian cancer – which will help to identify variation in quality of care and outcomes. For those services not covered by audit, the NHS Executive's cancer network also delivers a peer review programme, which identifies good practice and makes recommendations on how to improve service quality. It is vital we have the data and intelligence we need to support continued improvement and that is at the heart of our general approach set out in the National Clinical Framework and delivered by the NHS Executive.

I would also like to share some highlights of emerging and innovative service change from the recent national workshop on gynaecological cancers and would encourage the Committee to acknowledge the good work already underway. Health boards report a range of local actions including partnerships with industry to improve the efficiency of their local pathway design, the consolidation of local gynaecological services onto single sites with a much-enhanced offer to patients, the introduction of dedicated clinics for post-menopausal bleeding, greater use of straight to test approaches, pathway navigator roles to move people through pathways and coordinate teams, the training of nurse hysteroscopists, the incorporation of prehabilitation in the pathway, as well as improved digital interaction between referrer and service provider. Other notable service developments include more advanced forms of radiotherapy delivery, the introduction of long-term maintenance therapies, genomic and histopathological testing, and the introduction of robotic-assisted surgery. This offers an insight into the hard work health boards are putting in to improve services for people.

## **Prevention**

Our more general preventative approaches to population risk factors, including on smoking and obesity, will support improved outcomes and reduced incidence for gynaecological cancers. More specifically, the national HPV vaccination programme and cervical screening programmes are thought to be making significant inroads into cervical cancer incidence and mortality.

Uptake of the HPV vaccination was impacted during the pandemic due to school closures and access restrictions. Health board vaccination teams have made significant efforts to recover and increase uptake within the programme. As part of our National Immunisation Framework, we want everyone in Wales to understand the importance and benefits of immunisation. Working with PHW, we have developed a guide to vaccinations for young people in school years 7 to 11, which includes information on the HPV vaccination offer, being disseminated at the start of this academic year. PHW ran a targeted communications campaign over the summer on the benefits of HPV vaccination. We are also implementing the Joint Committee on Vaccination and Immunisation advice to move to a single dose HPV vaccine from this month (September) which will help to minimise disruption for schools and release capacity but still provide the same long-lasting protection.

Regular screening can reduce the risk of getting cervical cancer by 70%. Cervical screening is available to all women and people with a cervix in Wales aged 25 to 64 with approximately 70% taking up the offer. Like the vaccination programme, screening was impacted by the pandemic, but the programme was able to recover by December 2021. In response to UK National Screening Committee (UK NSC) recommendation, the use of high-risk HPV screening as the primary screen in the cervical screening programme was fully implemented in September 2018. This is a more specific test which means that a negative result is more accurate, and it will save more lives by determining a woman's risk of cancer earlier, which means the screening interval can be safely extended from three to five years. As such, from January 2022, the screening interval for people aged 25 to 49 who are HPV-negative has been extended to five years, bringing the interval in line with those aged 50 to 64. This change will support the screening programme to focus on those most at risk of cervical cancer. PHW launched an awareness campaign in June 2022 to build public understanding of HPV and reassure them that the change to screening interval is safe.

## Research

With so many types of cancer, many of which have a very low prevalence rate per country, in order to produce the evidence required to make the necessary improvements in prevention, diagnosis and treatment, cancer research must be seen as a global endeavour. It is important that we have a strong cancer research environment in Wales that can contribute to this global endeavour and support the delivery of research within our NHS. Over the years, cancer has been the single biggest area of Welsh Government health research investment. Significant government funding has built key cancer research infrastructure such as the Wales Cancer Research Centre, the Wales Centre for Primary and Emergency (including Unscheduled) Care Research, and the Centre for Trials Research.

Research into gynaecological cancers feature across a number of these. For example, in collaboration with Cancer Research UK, researchers from these centres have been assessing the impact of the Covid-19 pandemic on help-seeking behaviour in areas such as cervical cancer screening and sharing the rapid results with the NHS, public health agencies, and charity organisations to create new and relevant public health messaging. Further, gynaecological cancer is one of seven multi-disciplinary research groups (MDRGs) in Wales supported by the Wales Cancer Research Centre. These MDRGs connect pre-clinical and clinical researchers across a wide range of disciplines, sparking new collaborations, and ensuring that the broadest possible expertise shapes our future research ideas.

The previous Cancer Delivery Plan for Wales made a commitment to develop a cancer research strategy. The research and wider stakeholder community, with the support of Health and Care Research Wales, worked collaboratively to develop a way forward for cancer research in Wales. In July 2022, the Cancer Research Strategy for Wales was published with the aim of developing a collaborative, efficient, well-supported, and focused research community that will support increased research grant income to expand the research base, which will in turn seek to improve the prevention, diagnosis, and treatment of cancer. The WCRC work

programme has been reoriented to reflect the new strategy and received an additional £500,000 a year for a two-year period to catalyse activity.

The Wales Cancer Research Centre is providing strategic oversight and coordination for the implementation of the Strategy. It identifies six priority research themes where there is a strong track record of research excellence and future opportunity in Wales: precision and mechanistic oncology; immuno-oncology; radiotherapy; cancer clinical trials; palliative and supportive oncology; population health-based cancer prevention, early diagnosis, primary care and health services research. There are opportunities for gynaecological cancer to feature across all six priority research themes. Current activities across some of the themes include:

- Precision and mechanistic oncology: In collaboration with the Wales Cancer Research Centre, the Women's Health, Fertility and Cancer group based at Swansea University are leading the Cluster for Epigenomic and Antibody-drug conjugate (ADC) Therapeutics (CEAT) project which aims to advance a group of novel epigenetic drugs and ADCs to tackle ovarian cancer development and progression. CEAT is part of the Welsh Government and Industry backed SMART Expertise project part-financed by the European Regional Development Fund (ERDF). The research team are developing a pipeline of antibodies against different cancer targets and exploring the potential of using drugs that can modify cellular response, rather than killing healthy cells. If ADC works then it could become a first-line drug that could replace chemotherapy currently use in systemic treatment.
- Immuno-oncology: A Health and Care Research Wales PhD Studentship is currently investigating the value of repurposing drugs to treat chronic therapy-resistant ovarian cancer. Health and Care Research Wales are also supporting a consultant gynaecology oncology surgeon, via an NHS Research Time Award to develop research capacity focusing on vulval cancer.
- Cancer clinical trials: There are currently 17 related gynaecological cancer research studies open and recruiting patients across Wales, a combination of both interventional and observational. The studies range from trials looking at the cause and molecular genetics of cancers, cancer treatments, such as chemotherapy, and cancer drugs and their reactions.
- Population health-based cancer prevention, early diagnosis, primary care and health services research: A pilot is currently underway in Wales assessing a rehabilitation programme for people with advanced ovarian cancer (funded as part of women's health charity Ovarian Cancer Action's innovative UK-wide IMPROVE UK project).

## Women's Health Plan

In July 2022, I published the [Women and Girls Health Quality Statement](#) setting out what the NHS is expected to deliver to ensure good quality health services to support women and girls through the course of their lives. In December 2022, the NHS published the [discovery phase](#) of the NHS Women's Health Plan which was developed with significant input from women in Wales. The NHS Executive is currently establishing the Women's Health Network. The Network will be responsible for developing the 10-year Women's Health Plan which will detail how the NHS intends to realise the ambitions set out within the Quality Statement.

The Welsh Government's expectations with regard to the diagnosis and treatment of gynaecological cancers is set out in the Quality Statement for Cancer. Health boards and trusts are responding to these expectations through their local planning processes, which are scrutinised by the Welsh Government as part of the Integrated Medium Term Plan process. In support of this, the NHS has collaborated through the NHS Executive's predecessor to develop and publish a Cancer Improvement Plan. Taken together these policies and planning documents set out in detail what the NHS will do improve cancer services and outcomes, including for gynaecological cancer. It is not our intention to repeat these expectations in the Women's Health plan or to cut across the enhanced governance arrangements for cancer. The NHS Executive is already responding to these expectations with the introduction of a new national intervention, bringing together clinical, programme, data, and improvement expertise to bear on gynaecological cancer pathway improvement.

# Gynaecological cancers

## Engagement findings

June 2023

As part of the Health and Social Care Committee's inquiry into *gynaecological cancers*, the Citizen Engagement Team proposed a qualitative approach to engagement, comprising a series of interviews with women across Wales with lived experience of gynaecological cancers. This paper communicates the findings of those interviews.

### Background

1. The Health and Social Care Committee were interested to hear the lived experiences of women with symptoms of gynaecological cancers including how they are listened to and treated by healthcare professionals, and how services empower, care for and look after women diagnosed with gynaecological cancer (to ensure their physical, psychological and practical needs are met).

### Engagement

2. Working in partnership with cancer charity, Tenovus Cancer Care, the Citizen Engagement Team invited women with experience of gynaecological cancer to share their experience with the Committee. A screening survey was developed to enable women to potentially take part in the engagement.

3. Between 3 March 2023 and 2 May 2023 **five informal interviews** were conducted with women with lived experience of gynaecological cancers. Four of the interviews took place face-to-face and one online.



- 4.** The Committee viewed and considered the interviews, either in public or in private, on 27 April 2023 and 10 May 2023 respectively.
- 5.** The Citizen Engagement Team also received two written statements of evidence from women and relatives with lived experience of gynaecological cancers.
- 6.** Participants were encouraged to tell their stories in an unrestricted format but the following questions were asked to guide the conversation:
  1. What information is available and how much awareness is there about the risk factors for gynaecological cancers across the life course and the symptoms associated with gynaecological cancers?
  2. What barriers did/do you face to securing a diagnosis, such as symptoms being dismissed or confused with other conditions?
  3. Do you feel you are listened to by healthcare professionals and have your symptoms been taken seriously?

## **The videos**

- 7.** Further information about the interviews can be found on the Gynaecological Cancers inquiry [blog page](#).

## **Thank you**

- 8.** The Citizen Engagement Team would like to thank everyone who contributed to the programme of engagement, especially the courageous women willing to share their personal and poignant stories.
- 9.** Judith Rowlands passed away shortly after sharing her story. Thank you to the family of Judith Rowlands for their generosity and bravery.



# 1. Summary of recommendations

**10.** Participants suggested several ideas that they feel would improve the experiences of women with symptoms of gynaecological cancers:

**Recommendation 1.** Raising awareness of symptoms of gynaecological cancers via posters in surgeries and public places for example.

**Recommendation 2.** Support for GPs to be familiar with and knowledgeable about symptoms of gynaecological cancers.

**Recommendation 3.** A referral system to support GPs with early diagnosis when the patient is displaying symptoms of gynaecological cancers.

**Recommendation 4.** 'Keep in contact calls' asking for updates on symptoms and sharing potential waiting times with women waiting to be seen by medical professionals.

**Recommendation 5.** Proactively engaging with women not participating in the cervical screening programme to try and understand what barriers to participation they may have and consideration of potential additional support or alternatives to smear tests which might be possible.

## Claire



## Linda



## Judith



## 2. Key themes

### Awareness of symptoms

**11.** All participants strongly agreed that there is a general lack of awareness of symptoms of gynaecological cancers, especially in comparison to other types of cancers, for example, bowel or breast cancer.

“If you look around now, you don’t see any awareness of the symptoms of ovarian cancer.”

**12.** Some participants noted the need to address the misconception among many women in Wales that a clear cervical test means they do not have ovarian cancer.

**13.** Some participants mentioned how ovarian cancer is described as the ‘silent killer’ because it is argued that there are no symptoms. Participants disagreed with this and noted that there are symptoms, but women are not made aware of them and many in the health profession are not familiar with them either.

“I thought, I’m going to die purely for people’s lack of awareness of [ovarian cancer] and my lack of awareness...When I went to the hospital, I saw this list of the symptoms [on a poster] and I was just sat there thinking I’d literally ticked everyone.”

**14.** One participant suggested a referral system should be in place, due to a lack of awareness of symptoms among healthcare professionals.

**15.** Most of the participants suggested there should be more awareness raising of the symptoms of gynaecological cancers, for example, ovarian cancer.

**16.** Most participants suggested the need for information posters on the symptoms of gynaecological cancers to be displayed in medical surgeries and public places.

“The first poster I’d ever seen about ovarian cancer was in the waiting room when I was waiting to see the specialist. And I’d been diagnosed.”

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## Lack of knowledge from medical professionals

- 17.** All participants agreed that there is a general lack of awareness and knowledge of symptoms of gynaecological cancers within the medical profession.
- 18.** All participants mentioned that they had been misdiagnosed by their GPs, some participants had been misdiagnosed more than once.
- 19.** Participants explained that their GPs usually suggested that they had IBS, coeliac disease, acid in the stomach or were showing symptoms of the menopause.

“I knew that something wasn't quite right, and every time I went there I had a physical examination on my stomach and we all agreed there was something not quite right there. And every time I came away with a different kind of acid tablet.....It took three months and a locum [to diagnose the cancer].”

- 20.** All participants mentioned the lack of consistency between GPs. Participants were often seen by different GPs and given conflicting advice with different outcomes.

“Awareness of women's cancer symptoms at GP level is a key milestone that's being missed as well as the willingness to refer people for a scan, even if it's a negative scan. This should be made available to people.”

- 21.** One participant mentioned that she was seen by five GPs at her local surgery. None of them recognised that she was showing symptoms of ovarian cancer.
- 22.** One participant noted that GPs seem more aware of and had more knowledge about symptoms of some types of cancers, due to screening tests, for example, cervical cancer. This is not the case with ovarian cancer.

“The relationship with the GP remains fraught. To the extent that I wish I didn't have to go there. But I think you have to look at it positively because they are under pressure. And they have their own very difficult things to deal with. They are GPs and they can't be expected to know everything. In terms of ovarian cancer in particular, perhaps there needs to be something to come in to support them[GPs]. I wish they could be made aware.”

**23.** One participant mentioned her experience during secondary care when vital information was missed on a CT scan at Ysbyty Gwynedd. The participant was told she was cancer free but needed a hysterectomy. As a result, several organs had to be removed during hysterectomy surgery. This type of surgery should have taken place at a specialist hospital.

“I wish they would have sewn me back up and send me to The Christie, but they didn’t. I missed out on that opportunity and therefore I still have these pockets of disease, there are three on my liver and one by my stomach. These cannot be operated on.”

**24.** Another participant explained how she was informed by her cancer clinic at Ysbyty Gwynedd that her appointments would be reduced from three monthly appointments to six monthly appointments. On her return to the hospital, due to the pain, she was experiencing, she was admitted once again and told that there was a recurrence of the cancer.

“This is the cancer that was never going to come back, they’d never expect to see it coming back. I said, ‘What’s the prognosis?’ And he [consultant] came to the side of my bed and he said, ‘I’m so sorry, but at this stage it is incurable.’”

“Reflecting [on] where I am today, I do feel a victim of the NHS.”

### **Dismissed by medical professionals**

**25.** All participants noted that they felt they were being dismissed by medical professionals, either before, during or after diagnosis.

“I wasn’t listened to and I think that’s the most frustrating part of it.”

**26.** All participants suggested that they did not feel listened to by GPs and that they weren’t being taken seriously.

**27.** All participants felt that their GPs weren’t asking them the right questions and felt like they were being a nuisance.

“I was being received in a passive way and had to do a lot of chasing.”

**28.** One participant, later diagnosed with cancer, was told by her consultant that she did not have cancer in her body and that she needed to learn to manage her pain.

“He told me that everybody has problems in life and that my problem was the pain and that I needed to find a way to manage and live my life with the pain. And he said to me, ‘What do you think Christ was thinking when he was on the cross?’ And I believe. And he said to me that I could have a nerve block and a steroid injection and that he would call me, and I’m still waiting for that call.”

**29.** Another participant explained how she felt completely dismissed by her GPs who would not refer her for a scan.

“They told me, if they refer too many people for scans they get a black mark against their GP practice and that’s why they wouldn’t refer me initially....they were all women that I saw, which makes it even worse....Because of all this catalogue of mistakes, I’ve now got inoperable cancer.”

**30.** Another participant explained how she rarely went to see the GP but felt she had become a nuisance when she went to the surgery every two weeks because of her pain. She was told to change her diet or learn to live with the pain.

“You put your trust in professionals...13 years on, I’m still angry about it, because of what I went through.....I’d put off having children too as late as I could because I was very career driven. And they took that opportunity away from me.”

**31.** Another participant was told by her gynaecologist that she did not have cancer, only to find out two weeks later that she did.

“He [the gynaecologist] got her [the junior medic] to also examine me, and she was going, ‘No, I don’t think so’. And he dismissed her totally out of hand and told me I didn’t have cancer..... This gynaecologist who still practising was able to tell me that I didn’t have cancer and delayed treatment.”

**32.** Some participants mentioned the relief they felt when finally diagnosed.

“..my records say I was upset. I wasn’t upset though, I was relieved – I was so glad that someone had listened to me.”

“I was so pleased, because, at last, it wasn’t something that was in my head, I wasn’t making it up. They’d made me feel like I was making it up.”

**33.** Some participants noted how important it was that they were able to access support via cancer charities.

**34.** One participant mentioned that she is being supported by MacMillan and one of the priorities is to rebuild faith in the medical profession.

“I just have no trust. It impacts my mental health.”

**35.** Two participants noted the “humanity, empathy and kindness” shown to them at Velindre Cancer Centre. This made a positive difference at the time.

### **Delay of diagnosis**

**36.** All participants experienced a delay in diagnosis for their gynaecological cancer.

“There were several consultations with GPs where discussions about her symptoms were assumed to be perimenopausal, and, at some level, to be expected. Speaking to many female friends of a similar age to her, this is not an uncommon experience: in her case it led to a major delay in diagnosing cancer.”

**37.** All participants mentioned the devastating impact of the delay in their diagnosis.

“As it was, the planned start date for immunotherapy was the day after she entered an end-of-life care pathway.”

**38.** One participant mentioned that early diagnosis of ovarian cancer is crucial, otherwise the chance of survival is low.

**39.** Participants mentioned different reasons given for the delay in their diagnosis. Two participants mentioned how results went missing leading to a delay in diagnosis.

“The results initially went missing...you never know how much it has had an impact. Obviously...if I had been diagnosed [earlier]...perhaps I wouldn't have needed to have respiratory drains 5-6 times. Perhaps I wouldn't have been at the point that they didn't know if I was going to live beyond Christmas.”

### **Lack of communication**

**40.** Many participants mentioned their experience of having to chase information or results and how this enhanced their lack of confidence in the healthcare service.



**41.** One participant mentioned the hospital response when chasing an appointment date. The participant was told they were at least nine weeks behind and had been told not to book any more appointments as they were too busy. She was advised by her GP to consider seeking private medical healthcare if she was in a financial position to pay.

**42.** One participant mentioned how she was supposed to have chemotherapy within twelve weeks of her surgery but had not been contacted.

“I was ringing the hospital and being sent round and round and begging for someone to give me some chemotherapy because it was vital. But I ended up late having it. It’s been a bit of a disaster from start to finish.”

**43.** Another participant mentioned the lack of communication between GPs and hospitals.

“I was really annoyed and just felt that there is a lack of communication between GP practices and the NHS hospitals, and the messages are really confusing.”

## Patient and family care

**44.** Some participants spoke of their experiences whilst receiving treatment. One participant described her fear whilst a patient in one hospital ward.

“They transferred me to the....ward...[this] ward was dreadful. I was frightened there, I didn’t feel safe there at all.”

**45.** The participant mentioned how disorganised the ward was and how she suffered from serotonin syndrome, a potentially life-threatening condition, caused by too much serotonin being administered.

**46.** Another participant, a family member with lived experience of gynaecological cancer, mentioned his negative experience as a carer.

“My role as a prime carer was not always recognized or understood.”

**47.** The participant mentioned his lack of confidence in health professionals.

“I found that I was far more aware of dosages and timings for [her] prescribed medicines than the nursing team.”

**48.** One family member with lived experience of gynaecological cancer spoke of the lack of support for women not participating in the cervical screening programme.

### **Patients have to be their own advocates**

**49.** All participants mentioned having to be their own advocates, knowing they weren't well.

"We women know our bodies, and I knew it was not irritable bowel syndrome."

"We have to be our own advocates...we have to know about our symptoms. Not just with ovarian cancer, with everything ... but similarly, when you go and see a medic for advice, they have to know or they have to be able to refer you to someone else."

**50.** Some participants mentioned the crucial role of the third sector in supporting their advocacy.

**51.** One participant mentioned the challenge of being an advocate.

"Getting somebody to actually be accountable is so difficult....I've got cancer.....I want to be living my life and making the most of what I've got left."

### **Motivation to take part**

**52.** All participants were motivated to take part in the inquiry due to their lived experience of gynaecological cancers, especially the services or lack of services provided to them by healthcare professionals, either before, during or after their diagnosis.

**53.** All participants expressed that they wanted their stories to be heard to raise awareness of gynaecological cancer symptoms and to improve healthcare services available to women in Wales today.

**54.** All participants noted that they hoped sharing their lived experiences would help others accessing gynaecological cancer healthcare services in Wales.

“It shapes you.....that’s why I’m doing this. That’s why I’m here today. That’s why I’m campaigning because if I can stop another woman being in this position, it’s all worthwhile.”

“I made a vow that if I did survive it and which I have 13 years survival now, which is amazing in itself, I would raise awareness. So at any opportunity I raise awareness of the symptoms and just tell everyone my story.....there's no need for so many people to die of ovarian cancer because there are symptoms.”

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# Agenda Item 9

By virtue of paragraph(s) vi of Standing Order 17.42

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