Welsh Parliament
Health and Social Care Committee

Unheard: Women's journey through gynaecological cancer

December 2023

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About the Committee

The Committee was established on 23 June 2021. Its remit can be found at: **www.senedd.wales/SeneddHealth**

Current Committee membership:

Committee Chair: Russell George MS
Welsh Conservatives

Mabon ap Gwynfor MS
Plaid Cymru

Gareth Davies MS
Welsh Conservatives

Sarah Murphy MS
Welsh Labour

Jack Sargeant MS
Welsh Labour

Joyce Watson MS
Welsh Labour

The following Member was also a member of the Committee during this inquiry:

Rhun ap Iorwerth MS
Plaid Cymru

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Chair's foreword

"When you hear the sound of hooves, think horses, not zebras."

The above phrase is taught to medical students throughout their training and is based on the quote from Dr Theodore Woodward who said, "When you hear hoofbeats behind you, don't expect to see a zebra."

It means that doctors should first consider a more common, and often more likely, diagnosis before rarer options.

But zebras do exist! And for many women in Wales, this approach has led to them being sent away with a misdiagnosis, often of irritable bowel syndrome, when actually they have a gynaecological cancer. And sadly sometimes their true diagnosis comes too late.

It's clear from our inquiry that women feel their health concerns are not being taken seriously. Their symptoms are often dismissed or downplayed and in many cases they are made to feel like a neurotic nuisance.

Of course, we're not suggesting that every woman who visits their GP with symptoms of a gynaecological cancer has a bad experience. But it does seem that when things go wrong, they go badly wrong, sometimes with tragic consequences.

Ultimately, women know their own bodies. They know when something is wrong and those concerns must be listened to and acted upon.

This inquiry would not have been possible if women hadn't been prepared to share their stories with us and I would like to pay tribute to Claire, Linda and Judith for their incredible honesty and bravery. We trust that our report and recommendations for improvements will mean that other women will not have to go through what they did.

Russell George MS
Chair of the Health and Social Care Committee

Recommendations

Recommendation 1. The Welsh Government should work with the relevant health professional bodies and health boards to promote gender sensitivity and cultural competence among healthcare professionals. This 'relationship-based care' model should include ensuring there is adquate time for appointments to thoroughly address patients' concerns, and encouraging empathetic communication between patients and healthcare professionals, acknowledging the unique health needs and experiences of women. ..... Page 22

Recommendation 2. The Women's Health Plan for Wales should be completed and published before the end of the year, and the Welsh Government should support NHS Wales in doing this. The plan should include a specific focus on the gynaecological cancers, helping to improve women's health inequalities by raising awareness around the issues, improving access to health care and improving cancer outcomes for women diagnosed with a gynaecological cancer. ..... Page 23

Recommendation 3. In its response to this report, the Welsh Government should provide details of:

- the associated research budget to support the women's health plan, and
- what the research priorities will be, including whether there will be specific funding for gynaecological cancer research. ..... Page 23

Recommendation 4. The Welsh Government should work with health boards to ensure that an assessment is made of gynaecological cancer-related services lost during the Covid-19 pandemic, and ensure those services are reinstated as a matter of urgency. In its response to this report, the Welsh Government should:

- report back on the timings for re-instating those services and,
- where services are not being reinstated, provide an explanation for this. ..... Page 27

Recommendation 5. The Welsh Government should provide a set of clear and measurable objectives and targets for the NHS Executive in relation to improving gynaecological cancer outcomes, setting out how they are aligned to the work of

screening does not test or screen for other gynaecological cancers, and includes information about the symptoms of other gynaecological cancers. This information should also be provided when women attend their breast screening appointment. ..... Page 54

Recommendation 12. The Welsh Government should work with Public Health Wales, and community leaders and organisations to develop and implement a series of campaigns to raise awareness about the symptoms of gynaecological cancer. These campaigns should:

- be re-run frequently, and should encourage women to seek medical attention promptly if they experience any symptoms;
- include clear messaging to better engage the public in the promotion of healthier lifestyle choices and the personal benefits associated with these choices;
- include consideration of cultural, linguistic and socio-economic factors and be targeted at specific populations and communities that are disproportionately affected by health inequalities. ..... Page 54

Recommendation 13. In its response to this report, the Welsh Government should provide details of any plans it has to evaluate the decision support tool, 'Gateway C', to see what impact it is having on GP referral rates. ..... Page 63

Recommendation 14. The Welsh Government should work with the relevant professional bodies and NHS Wales to:

- ensure continuing medical education opportunities have an appropriate focus on gynaecological cancers. This should include a conference/webinar to update GPs on the latest guidelines and diagnostic techniques focused on gynaecological cancers to take place by the end of March 2024;
- ensure the clinical guidelines that outline the symptoms and risk factors associated with gynaecological cancers are clear and being implemented. This should include an audit of GP referrals and patient outcomes related to gynaecological cancers to provide feedback to GPs to help them improve their diagnostic skills;
- provide GPs with support from secondary care to assist them in the assessment and referral of patients with potential gynaecological cancer

symptoms. For example, telemedicine solutions that allow GPs to consult with specialists remotely (this can be particularly useful for GPs in rural or underserved areas). ..... Page 63

Recommendation 15. The Welsh Government, in conjunction with the Wales Cancer Network, should commission an urgent review of the incidence, trends and high-risk populations in relation to emergency presentations with a gynaecological cancer, broken down by each of the gynaecological cancers. This review should include access to primary care, symptom recognition amongst GPs, misdiagnosis and communication and referral processes. The findings should be shared with the Committee within six months of the publication of this report. .....Page 65

Recommendation 16. The Welsh Government should clearly outline its ongoing commitment to prioritising gynaecological cancer and to providing the essential attention and resources required to positively impact women's health. To ensure continual improvement in gynaecological cancer care, the Welsh Government should work with the NHS Executive to consistently publish key performance data for the cancer interventions (such as waiting times, patient outcomes, and access to care), promoting transparency and better women's health outcomes. ..... Page 72

Recommendation 17. The Welsh Government should work with the All Wales Medicines Strategy Group and relevant professional bodies to:

- improve understanding of the challenges of implementing new NICE recommended drugs to help alleviate some of the frustrations and misunderstanding there is among healthcare professionals;
- address some of the challenges facing health boards in implementing new NICE-recommended drugs, setting out a plan for how they will ensure there will be sufficient capacity to allow women in Wales, diagnosed with a gynaecological cancer, to benefit from prompt access to these new treatments. This should include an analysis which new cancer drugs for treating gynaecological cancer are likely to be approved in the short to medium term. ..... Page 73

Recommendation 18. The Welsh Government should write to all health boards to remind them of their duty to ensure that all patients are treated with dignity and respect. ..... Page 73

1. Introduction

Background

1. According to Cancer Research UK, one in two people will be diagnosed with cancer at some time in their lives.[1]

2. Among the different female-associated cancers, breast cancer has the highest incidence and death rate, followed by gynaecological cancers. These cancer types can affect women, some transgender men and non-binary people assigned female at birth (anyone with female reproductive organs can be at risk of gynaecological cancers).

3. Each year, around 1,200 people are diagnosed with a gynaecological cancer in Wales. Symptoms vary between different types of gynaecological cancers, and each have different treatment pathways, and affect women and girls in different ways. Some symptoms can include bloating, pelvic pain, bleeding between periods, pain during sex, itching and unusual vaginal discharge. Some gynaecological cancers can present late, with non-specific symptoms (such as ovarian cancer).

4. The five most frequent types of gynaecological cancer are: cervical, ovarian, endometrial (also known as womb or uterine), vaginal and vulva.

5. The incidence rate for gynaecological cancer in Wales is higher than the UK average,[2] as is the mortality rate.[3]

6. Each year around 470 people die from gynaecological cancers in Wales.[4]

[1] Cancer Research UK: 1 in 2 people in the UK will get cancer
[2] In Wales the incidence rate is 72 cases per 100,000 female population, compared to the UK average of 68 cases per 100,000 female population, using the European age-standardised incidence rate for 2016-18 [the most recent figures provided at the time of the inquiry]
[3] In Wales, the mortality rate is 26 deaths per 100,000 female population, compared to the UK average of 24 deaths per 100,000 female population, for 2017-19 [the most recent figures provided at the time of the inquiry]
[4] Cancer Research UK: Cancer statistics for the UK

Our inquiry

7. Our strategy for the Sixth Senedd[5] identified women's health as a priority. We decided to focus our inquiry on gynaecological cancers and the experiences of women with symptoms of gynaecological cancers, in particular:

- The information available and awareness about the risk factors for gynaecological cancers across the life course and the symptoms associated with gynaecological cancers.
- The barriers to securing a diagnosis, such as symptoms being dismissed or confused with other conditions.
- Whether women feel they are being listened to by healthcare professionals and their symptoms taken seriously.
- 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.
- 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.
- 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.
- 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).
- 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.
- 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

[5] Sixth Senedd strategy, December 2021

the leadership and innovation needed to improve cancer survival rates for women.

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

8. We gathered evidence in writing[6] and by holding oral evidence sessions with stakeholders, including the Minister for Health and Social Services (the Minister).

9. In addition, our Citizen Engagement Team has been working with Tenovus Cancer Care[7] to record a series of videos[8] with women who have experienced a gynaecological cancer.

10. We are extremely grateful to everyone who shared their story with us.

[6] Health and Social Care Committee, Consultation: Gynaecological cancers
[7] Tenovus Cancer Care
[8] Gynaecological cancers: Are women being taken seriously?

2. Listening to women

11. It is clear from the written and video evidence we received that many women feel they are not being listened to by healthcare professionals.

12. The Royal College of Nursing (RCN) Wales said:

> *"It is important that women feel comfortable disclosing symptoms that they may find uncomfortable to talk about, and that these symptoms are recognised and addressed quickly, making sure the woman feels listened to."*[9]

13. Jo's Cervical Cancer Trust reported that, of 10 women in Wales who spoke to their GP about possible gynaecological cancer symptoms, 12% felt their concerns were not taken seriously, 6% were told to wait for their cervical screening, and 6% were told to come back later if their symptoms didn't change.[10]

14. Claire O'Shea, a cancer patient who has experienced gynaecological services in Wales, and who documented her experiences on video, told us:

> *"Primary care and my experience with my GP was [ ], disappointing, to say the least; so many phone calls, me chasing, being dismissed. I called it medical gaslighting by the end, and I think the reason I ended up in tears with the final GP appointment was finally feeling vindicated, like I'm not a neurotic woman who's making a fuss over nothing, which is definitely how I was made to feel."*[11]

15. In her video evidence, Judith Rowlands said:

> *"I had such bad pain, terrible pain, that originated in my tummy, went through to my back, affected my leg so badly I couldn't walk, and I couldn't understand why a pain in my tummy was affecting my mobility. But I just couldn't—I could not walk because of the pain. I was so poorly with the infection, with the pain, and I kept saying, "I think I've still got cancer." "No, definitely not, no. We'd never expect to*

[9] GC16 Royal College of Nursing Wales
[10] GC10 Jo's Cervical Cancer Trust
[11] RoP [para 14], 27 April 2023

> *see that your cancer would come back, and if it did come back you'd be older and it would affect you in a different way."*[12]

16. Sadly, Judith's cancer had come back and by the time it was diagnosed, it was incurable. Judith passed away in May, shortly after her video was shown in Committee. We're grateful to Judith's family for allowing us to continue to tell her story in the hope that other women won't have to go through what she did.

Empowering women

17. The reason women are not always being listened to by healthcare professionals can be attributed to various factors. Gender bias can influence how healthcare professionals perceive and interact with female patients. Stereotypes and preconceived notions about women's emotions, pain tolerance, or health concerns can lead to dismissive attitudes. Women's symptoms may be underestimated or attributed to psychological or emotional factors rather than thoroughly investigated leading to delays or missed diagnoses.[13]

18. Claire O'Shea told us:

> *"I didn't feel there was, like, much emotional connection or empathy sometimes, and I felt like a neurotic middle-aged woman who had nothing more to worry about than something like physical discomfort. And then, it was when I saw the woman GP who just vindicated, made me feel understood, let me be emotional about it, told me what I was worried about was worth being worried about, and that just changed my journey from there on out."*[14]

19. There has also been a lack of medical research on female subjects, leading to misdiagnoses or inadequate care for women.

20. Healthcare providers often face time constraints too, which can limit their ability to engage in thorough conversations with patients, including women, about their concerns.

[12] RoP [para 19], 10 May 2023
[13] GC08 Women's Health Wales Coalition, GC09 Fair Treatment for the Women of Wales
[14] RoP [para 24], 27 April 2023

21. While the focus must be on 'fixing the system', it is also important to empower women to speak up for their health, ensuring they receive the care and attention they deserve. Target Ovarian Cancer, told us:

> *"I think empowering women is really important, so empowering women to know that their GP should be listening to them, and if they're not happy with, particularly, their GP, but also, through the secondary care experience, if they're not happy with the treatment that they're getting or the support that they're getting, empowering them to ask more questions and trying to get that help. But it does rely, fundamentally, on healthcare professionals taking those symptoms seriously."*[15]

22. When asked about potential gender bias, Dr Zohra Ali of the British Islamic Medical Association (BIMA) said she recognised there are instances of women struggling to be heard. She highlighted the importance of empowering women to make their voices heard:

> *"I think it's also about wider enablement, so helping them to be more empowered to overcome any of these biases that they feel they may be experiencing."*[16]

23. Dr Shanti Karupiah from the Royal College of GPs (RCGP) said women should be encouraged to seek second opinions and advocate for their health to ensure they receive the care they need and deserve. But some women may not feel empowered to assert their needs and concerns during medical appointments. Within general practice, this is compounded by difficulties getting an appointment and difficulties accessing a female GP. The RCGP told us:

> *"We have to empower our women patients with the knowledge and the knowledge that they need to approach any of the health professionals, if they have any concerns, no matter how small, and never feel that they can't."*[17]

[15] RoP [para 38], 10 May 2023
[16] RoP [para 187], 10 May 2023
[17] RoP [para 208], 10 May 2023

Women's Health Plan

24. In its report 'Better for Women'[18] published in December 2019, the Royal College of Obstetricians and Gynaecologists (RCOG) recommended that the four UK nations should publish a women's health plan to address areas of unmet need for women's health. The Scottish Government published its women's health plan in August 2021 and the UK Government published its women's health strategy for England in the August 2022.

25. In July 2022, the Welsh Government published the Women and Girls Health Quality Statement[19], setting out what the NHS is expected to deliver to ensure good quality health services to support women and girls though the course of their lives.

26. The Deputy Chief Medical Officer told us:

> *"... the women and girls' health quality statement is founded, I think, on the principle that women have, in the past, not always been heard. You know, there is increasing evidence of that that a lot of medical training and experience has been within a kind of male frame. And women do feel very, very concerned about the symptoms that they get, and I know that there is a lot of evidence that, over the years, women haven't been listened to adequately."*[20]

27. In December 2022, the NHS published the discovery phase of the NHS Women's Health Plan[21]. The Plan, which will be developed by the Women's Health Network[22], will detail how the NHS intends to realise the ambitions set out within the Quality Statement over the course of the next 10 years.

28. The Minister told us that she does not intend to include gynaecological cancers specifically in the women and girls' health plan because she did not want to overcomplicate the system. She did say there would be a focus on listening to women within the plan:

> *"One of the things that I think is clear is that women quite often are not listened to, they feel that they are ignored and so on, and I think*

[18] Better for women: Improving the health of women and girls,
[19] The Quality Statement for women and girls' health
[20] RoP [para 19], 21 September 2023
[21] Women's Health in Wales - A Discovery Report
[22] The Women's Health Network is currently being established by the NHS Executive.

> *that's the kind of thing that I'm very keen to see emphasised within the women's health plan. So, it won't be specifically cancer, but it'll be things around some of the frustrations that I'm sure you've heard in some of the evidence."*[23]

29. When asked during our general scrutiny session on 8 November 2023 about the timescales for the delivery of the women's health plan, the Minister told us:

> *"This is now an NHS health plan, so this is not going quite as quickly as I'd hoped. But what we are doing is we're in a situation now where we've got the quality statement that's been delivered already, and progress has been made with the establishment of the women's health network.*
>
> *So, the plan is an NHS plan. I can't determine what they're going to do, because it's their plan—it's the NHS plan. I do the quality statement, they do the delivery."*[24]

30. She went on to say that progress has been made with the establishment of the women's health network:

> *"We've recruited, or we're in the process of recruiting, two key posts in terms of the clinical lead and a network manager, and those appointments are anticipated for December. But we're not waiting for that. There's actually quite a lot of work being done in the background. We've got a transitional senior leadership group, which is preparing documentation ready for the establishment of that network."*[25]

Our View

31. A strong theme that came through in the evidence we heard on this inquiry was that many women continue to feel unheard in healthcare settings.

32. The women we spoke to told us that some healthcare professionals are not taking women's symptoms or concerns about their health seriously, and that this

[23] RoP [para 14], 21 September 2023
[24] RoP [paras 152 and 154], 8 November 2023
[25] RoP [para 152], 8 November 2023

can lead to underdiagnosis or delayed treatment, both of which can have devastating consequences.

33. We also heard that some healthcare professionals are not communicating effectively or establishing rapport with patients, making women feel unheard or dismissed. Further, that women from diverse cultural backgrounds or those with lower socioeconomic status may face additional barriers to being heard in healthcare settings.

34. Not every woman who visits their GP with symptoms of a gynaecological cancer has a bad experience. But when things go wrong, they can go badly wrong, sometimes with tragic consequences. Women know their own bodies and know when something is not right so their concerns should be listened to and acted upon.

35. It is clear that women's health needs to be given a higher priority than has previously been the case. Women need to access the care they need when they need it. The health service needs to be responsive in providing that care. Most importantly, it needs to listen to women and respond to their health concerns appropriately.

Recommendation 1. The Welsh Government should work with the relevant health professional bodies and health boards to promote gender sensitivity and cultural competence among healthcare professionals. This 'relationship-based care' model should include ensuring there is adequate time for appointments to thoroughly address patients' concerns, and encouraging empathetic communication between patients and healthcare professionals, acknowledging the unique health needs and experiences of women.

36. Given all of the above, it is extremely disappointing that Wales still does not have a women's health plan. This is particularly surprising as gynaecological cancers have the highest incidence and death rate of the female-associated cancers, after breast cancer. We believe this plan should be finalised and published as a matter of urgency. Further, we believe that there should be specific reference to gynaecological cancers within the plan as a means of driving improvements in women's health inequalities.

37. As part of the work currently underway to develop the women's health plan, there needs to be consideration of how new initiatives such as the women's health hub in Cwm Taf Morgannwg UHB and consolidated gynaecological services could help to improve early diagnosis of gynaecological cancers.

Recommendation 2. The Women's Health Plan for Wales should be completed and published before the end of the year, and the Welsh Government should support NHS Wales in doing this. The plan should include a specific focus on the gynaecological cancers, helping to improve women's health inequalities by raising awareness around the issues, improving access to health care and improving cancer outcomes for women diagnosed with a gynaecological cancer.

Recommendation 3. In its response to this report, the Welsh Government should provide details of:

- the associated research budget to support the women's health plan, and
- what the research priorities will be, including whether there will be specific funding for gynaecological cancer research.

3. The impact of the COVID-19 pandemic

38. Despite plans to maintain cancer treatment during the COVID-19 pandemic, there has been widespread disruption. The Cancer Improvement Plan for NHS Wales 2023-2026 states:

> *"The pandemic has significantly exacerbated the existing fragilities in the wider healthcare and cancer system which is struggling to deliver the evidence-based services, capacity and workforce that are required to recover and improve cancer services."*[26]

39. Screening programmes, including cervical screening were put on hold at the beginning of lockdown. Women had their screening appointments delayed or cancelled.

40. Another area heavily affected was the number of people being urgently referred with suspected cancer symptoms. According to Cancer Research UK (CRUK), fewer people were referred than normal during the pandemic but the data is now showing that referrals are above pre-COVID figures (which reflects the backlog of people who didn't go to their GP or weren't referred during lockdown and who still have concerns or symptoms).[27]

41. The Minister's written evidence agrees:

> *"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."*[28]

42. Richard Peevor, a consultant gynaecological cancer surgeon in Betsi Cadwaladr UHB and representing the Royal College of Obstetricians and Gynaecologists (RCOG) explained that, post-COVID, there has been "a real boom" in urgent suspected cancer referrals. He believes the increase in urgent referrals is due to pressures elsewhere in the system:

[26] Wales Cancer Network: A Cancer Improvement Plan for NHS Wales 2023-2026
[27] Cancer Research UK: What happened to cancer services during the COVID-19 pandemic
[28] HSC Committee, 21 September 2023, Paper 1

> *"GPs are struggling to get routine or urgent patients seen in secondary care, because of very long waits of over a year for a secondary care appointment. And so what GPs are having to do is they're having to send patients in as a suspected cancer referral, and they're wording the referral letters so that we have to see them."*[29]

43. Cancer Research UK (CRUK) say normally around a third of people with cancer are diagnosed through the urgent suspected cancer referrals route. Other patients begin a cancer pathway with a referral for suspected cancer, either from a GP or national screening service, followed by an outpatient appointment with a consultant, and then a diagnosis. Others are diagnosed via an emergency presentation, such as at A&E.

44. We also know there are very long waits for gynaecological cancer treatment. Performance is very poor for the gynaecological cancers, with compliance consistently below the 70 per cent single cancer pathway target, with gynaecological cancer one of the lowest of all cancers reported (39 per cent in August 2023).

45. The RCOG told us that the large number of urgent suspected cancer referrals is impacting on performance against the single cancer pathway, stating:

> *"if you breach in that first two weeks, if it's taken three or three and a half weeks to see a patient because of capacity, then you just can't catch up on the 5 per cent of patients who do have a cancer."*[30]

46. Whilst this may help to explain some of the poor performance in cancer waiting times, it is clear there are wider issues in the system. Dr Louise Hanna, representing the Wales Cancer Network's Gynaecological Cancer Site Group referred to "significant capacity issues", including a lack of resources, facilities and workforce:

> *"We've got pressures on theatre space, we've got pressures on radiotherapy, on chemotherapy. We've got services [ ] that were lost during COVID and haven't been reinstated. I would've thought an immediate action would be to survey, within Wales, what services*

[29] RoP [para 191], 27 April 2023
[30] RoP [para 191], 27 April 2023

> *were lost due to COVID and to reinstate those immediately, because we need to go beyond where we were before COVID."*[31]

47. The Wales Cancer Alliance (WCA) agrees but says that NHS Wales wasn't performing well pre-pandemic and "we're still not at a point where our diagnostics, our radiology, our pathology, is up to scratch". The WCA said "we can't blame COVID for that" adding, "we knew about these problems…we should have been preparing for this 10 or 15 years ago".[32]

48. Professor Tom Crosby, the clinical lead for the Wales Cancer Network, dismissed the suggestion that delays in treatment were specific to the gynaecological cancers:

> *"It's not specific to gynaecological cancers; we can look at breast cancer and prostate cancer as well, for women and men. Demand is outstripping capacity; we know that. The problem with capacity is workforce, and that's not easy to fix overnight."*[33]

Our view

49. While the pandemic inevitably had an impact, it is clear there are long-standing issues in gynaecological cancer services which pre-date COVID-19. Waiting times for gynaecological cancer treatment are very long and compliance with the single cancer pathway target is the lowest for all reported cancers. We also heard of significant capacity issues including a lack of resources, facilities and workforce.

50. We heard of services that were lost due to COVID-19 that have still not been reinstated. We agree with witnesses that the Welsh Government needs to work with health boards to make an assessment of the services that have been affected and reinstate them as a matter of urgency.

Recommendation 4. The Welsh Government should work with health boards to ensure that an assessment is made of gynaecological cancer-related services lost during the Covid-19 pandemic, and ensure those services are reinstated as a matter of urgency. In its response to this report, the Welsh Government should:

[31] RoP [para 302], 27 April 2023
[32] RoP [para 112], 10 May 2023
[33] RoP [para 313], 27 April 2023

- report back on the timings for re-instating those services and,
- where services are not being reinstated, provide an explanation for this.

4. Leadership and accountability

51. The Welsh Government published its Quality Statement for Cancer[34] in May 2022. 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.

52. 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.

53. In her written evidence, the Minister says that she has made cancer one of her 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."*[35]

54. The NHS in Wales has also collaborated to develop a national response to the Quality Statement. The Cancer Improvement Plan for Wales[36], published in January 2023, sets out how the NHS will respond.

55. Professor Tom Crosby, as clinical lead for the Wales Cancer Network is also the lead for the Cancer Improvement Plan. The plan sets out how cancer services are going to be delivered by NHS Wales - via health boards and trusts. The Plan sets out the ambition for Wales to improve cancer outcomes and reduce health inequalities. It states:

[34] The Quality Statement for Cancer, May 2022
[35] HSC Committee, 21 September 2023, Paper 1
[36] A Cancer Improvement Plan for NHS Wales 2023-26

> *"There are major opportunities to review the way we deliver services; breaking down organisational boundaries that stand in the way of equity of access, and consistency and efficiency in the delivery of care."*[37]

56. The plan states that government support and leadership is needed to address areas such as health inequalities, workforce, diagnostics infrastructure and capacity, and data and intelligence. However, Professor Crosby told us that:

> *"system leadership, accountability and oversight…has possibly gone backwards".*[38]

57. He said there is a real issue of accountability at the moment:

> *"We've just established the NHS executive, which has come into force from 1 April. That has oversight of delivery of healthcare services across organisations in Wales. I think the Welsh Government's response will be that the health boards have a lot of funding and all the funding that they require. But in terms of accountability and holding to account, I think there are issues that we need to improve on."*[39]

58. When asked where accountability for improving cancer patient outcomes lies, Professor Crosby responded:

> *"The ultimate responsibility in governance and accountability has to lie with Welsh Government oversight. You can charge that responsibility through Judith Paget and the director general in terms of oversight of the health boards, and we will work with the health boards to report and share best practice, particularly across organisational boundaries, some of which show significant variation… But ultimately, the only oversight body that has the authority, the mandate and the funding, I'm afraid, is the Welsh Government."*[40]

[37] A Cancer Improvement Plan for NHS Wales 2023-26
[38] RoP [para 394], 27 April 2023
[39] RoP [para 284], 10 May 2023
[40] RoP [para 296], 27 April 2023

59. The Minister pointed out that the NHS Executive had only commenced its work in April, so needed more time to establish its ways of working.[41] The Minister also referred to a new group she has set up to look at governance and accountability within the NHS.

60. The Deputy Chief Executive NHS Wales, Welsh Government, added:

> *"So, I think there's a very clear governance framework around the improvements that we're trying to seek, but I think it's important to state that this will take a degree of time to implement."*[42]

Regionalisation

61. The Cancer Improvement Plan for Wales 2023-26 states that there needs to be a greater focus on regional working, including the establishment of regional waiting lists for some diagnostics and treatments. However, we heard that most cancer surgery is embedded and delivered within local health board boundaries and multidisciplinary teams (MDTs). Currently, services also tend to be disrupted by unscheduled care pressures.

62. Witnesses raised concerns about the variation between health boards' performance. The Cancer Improvement Plan for NHS Wales 2023-2026 states:

> *"...[cancer] outcomes such as survival are not as good as we would like. Difficult as it is to see how poorly our outcomes compare with similarly developed countries, it is even more unacceptable to see the variation in outcomes within our own country, between regions and even within a single Health Board boundary."*[43]

63. Professor Crosby explained:

> *"We've seen in south-east Wales and south-west Wales, between organisations that are just 10 to 15 miles apart, there's 1.5 to twofold variation in performance across the pathway."*[44]

[41] RoP [para 34], 21 September 2023
[42] RoP [paras 41-42], 21 September 2023
[43] A Cancer Improvement Plan for NHS Wales 2023-26
[44] RoP [para 313], 27 April 2023

64. The Minister acknowledged there was inconsistency across Wales in terms of cancer services, and said:

> *"I think that's crucially important, because I do think there is inconsistency in terms of how things work across Wales in terms of cancer. And I think the NHS exec has some work to do in that area, first of all, to carry out an analysis of the data, to look at what's working well and to learn from those examples, and ensure that we roll out that good work to the areas facing greater challenges. And I do think that that is part of the responsibility of the clinical network led by Tom Crosby. So, I do think it's part of their role to ensure that we do see that inconsistency being dealt with."*[45]

65. Professor Crosby's evidence raises questions about the role of the NHS Executive and whether it provides the level of regional accountability needed to drive improvements.

66. Regional working is considered to be a solution to some of the barriers to providing timely care, and facilitating regional working in terms of funding, mandate and authority to work differently across organisational boundaries is key to that. Professor Crosby explained:

> *"Workforce is the biggest issue, and we need to have those medium to longer term plans for the workforce to improve, but, in the meantime, we need to use what capacity we do have to the best of our ability, and that must mean working across organisational boundaries."*[46]

67. The Wales Cancer Alliance (WCA), said:

> *"There are barriers at the moment to regional working, based on the way that our health boards are set up. So, I know that the Wales cancer network, in particular, are trying to break down those barriers so that we can do more things collectively across regions. We've got a massive health board in north Wales, which, in itself, needs to break*

[45] RoP [para 45], 21 September 2023
[46] RoP [para 371], 27 April 2023

> *barriers within its own patches, so there are huge issues. That takes leadership, culture change."*[47]

68. Dr Louise Hanna, representing the Wales Cancer Network Gynaecological Cancer Site Group, agreed. She told us that gynaecological cancers are fairly uncommon compared to other types of cancer, and so there are small teams of healthcare professionals working in this field within the health boards. She says this means that there is a lack of resilience within teams, and the way to address that is to work on a regional basis.

69. The Minister acknowledged the difficulties outlined by Dr Hanna:

> *"If you have one or two people who are experts and one of them goes on holiday or goes off sick, then obviously the system is under huge pressure, whereas actually if you've got a group of people working together who are experts and one of them goes on holiday, then the cover is just easier for everybody. So, that's why if what you want is resilience in the system, we are going to have to move towards a more regional approach, and that's exactly what we're looking to do."*[48]

70. The Deputy Chief Executive of NHS Wales told us that part of the planned care recovery fund included a set of proposals around funding for regional diagnostics—hubs and centres, one in each of the three regions - south-east, south-west and the north. He said:

> *"What we have got already is regionalisation of specialist cancer services. So, patients are referred for particular treatment into tertiary centres, such as Cardiff, Swansea or in north Wales. So, we need to just expand that so that it becomes clearer how patients get equal access then to services across different parts of the region.*

71. The Deputy Chief Executive of NHS Wales told us that regionalisation isn't as easy as it sounds. He highlighted the complexity of merging patient treatment lists across health boards.

[47] RoP [para 97], 10 May 2023
[48] RoP [para 54], 21 September 2023

Rapid Diagnostic Clinics

72. Diagnostic tests are key to determining whether cancer is the cause of a patient's symptoms and signs. As with all cancers, speedy access to these tests are key. The earlier cancer is diagnosed, the easier it is to treat and the better the prognosis. The Cancer Improvement Plan for NHS Wales 2023-26 states:

> *"Data shows that the demand and the volume of patients who are in the system with a suspicion of cancer is growing, with the capacity of diagnostics unable to reduce the volume on the waiting list. There is therefore an urgent need to increase diagnostic capacity across all tests, procedures and reports in a timely manner."*[49]

73. Rapid Diagnosis Clinics (RDCs) have been set up to enable patients with potentially serious but non-specific symptoms suspicious of cancer to be referred in a timely way. The RDCs are intended to speed up the diagnosis process as tests are carried out by a specialist team "then and there". So, for example, a patient could have an ultrasound, biopsy, hysteroscopy all on the same day. RDCs have been rolled out across Wales.

74. The Royal College of GPs (RCGP) told us:

> *"We tend to refer patients with any vague symptoms. When I say 'vague', it's not the classical red flags; it's anything from extreme tiredness to just a symptom that doesn't fit into the right pathway of referrals that's existing. And GPs refer into this centre, and they run two half-day clinics per week. They tend to see patients within one week of GP referral, and the patients tend to get an answer within that same day or the next day."*[50]

75. The British Islamic Medical Association (BIMA) said it supports the roll out of RDCs to help speed up the diagnostic pathway:

> *"There can be quite a protracted and prolonged route to getting the appropriate investigations done, particularly if people aren't being referred down the two-week pathway because they have vague symptoms... So, akin to how the rapid diagnostic breast services have*

[49] A Cancer Improvement Plan for NHS Wales 2023-26
[50] RoP [para 178], 10 May 2023

> *been set up, where women have this one-stop area where they can come, have their scans done and be examined, and any additional tests."*[51]

76. RDCs can also help reduce anxiety for patients awaiting cancer diagnoses by providing quicker access to diagnostic tests. We heard from Claire O'Shea about the anxiety associated with waiting for test results:

> *"So, for me, I felt like I had a death sentence. I just sat there for two days thinking about how I'd tell people and it was awful."*[52]

77. The Minister confirmed that there are currently eight rapid diagnostic centres in Wales, with three in north Wales:

> *"So, I think that's positive. You know about the financial constraints we're under at the moment, in particular in relation to capital. So, I think it will be difficult for us to go much further for the time being. But I think we're very pleased that these have been set up."*[53]

Our view

78. Gynaecological cancers are more complex than lots of other cancers. There are different types of gynaecological cancers; some are more prevalent than others, and some have symptoms that make them easier to diagnose than others. They all present differently and therefore require different diagnostic approaches and different clinical pathways. For those reasons, we believe there needs to be strong leadership and support around the work on gynaecological cancers.

79. While we understand the principle behind the Cancer Improvement Plan being owned by NHS Wales, we feel strongly that the Welsh Government must be more accountable for ensuring that gynaecological cancer services are effective and responsive to the needs of women.

80. We are concerned that there appears to be uncertainty between the Welsh Government, the NHS Executive and the Wales Cancer Network about their different roles and responsibilities in supporting the delivery of the gynaecological cancer pathways. This needs to be addressed immediately. It's also unclear how

[51] RoP [para 213], 10 May 2023
[52] RoP [para 17], 27 April 2023
[53] RoP [para 125], 21 September 2023

the Minister's governance and accountability group will fit into these existing structures.

Recommendation 5. The Welsh Government should provide a set of clear and measurable objectives and targets for the NHS Executive in relation to improving gynaecological cancer outcomes, setting out how they are aligned to the work of the Wales Cancer Network and the Cancer Improvement Plan priorities. It should do this at the time of responding to this report.

81. It is also concerning to hear that different ICT systems in the health boards may be a barrier to regional working. It's not right that the benefits of regional working, which could reduce waiting times for consultations, diagnostics and treatment, and make services more sustainable, are not being realised due to difficulties merging patient treatment lists. Health Boards must work together to resolve that. In the meantime, there needs to be a greater focus on how patients get equal access to gynaecological cancer services across different parts of Wales.

82. Anything that can help speed up the diagnosis and testing process is to be welcomed. We heard that RDCs are based on good practice from Denmark and that there is evidence that RDCs have the potential to be valuable tools for detecting cancer early and improving patient outcomes. However, it's important that continuous evaluation and improvements of the RDCs is undertaken to optimise their performance and ensure that they contribute effectively to early cancer detection in Wales.

83. Early detection of cancer often leads to more favourable treatment and improved survival rates and so it's positive to hear that RDCs can contribute to this by shortening the time between initial suspicion and diagnosis, particularly for patients who present to their GP with vague symptoms that might otherwise not be investigated.

Recommendation 6. The Welsh Government should set out how it intends to support health boards to maximise the benefits of regional working, specifically to overcome the barriers facing services due to the incompatibility of ICT systems. It should do this at the time of responding to this report.

Recommendation 7. The Welsh Government should undertake an evaluation of the Rapid Diagnostic Centres (RDCs) to optimise their performance and ensure that they contribute effectively to early cancer detection. This should include ensuring that patients get equal access to RDCs across different parts of Wales, in

particular underserved areas. It should report back to us with the findings of the evaluation within 18 months of publication of this report.

5. Cancer prevention

Risk factors for the gynaecological cancers

84. The risk of developing a gynaecological cancer increases with age (as with other cancers), and so with an ageing population we can expect more women to be diagnosed with a gynaecological cancer as they get older. However, other risk factors are modifiable. The Cancer Improvement Plan for NHS Wales 2023-26[54] states that around 4 in 10 (37.8%) cancer cases in Wales each year could be prevented.

85. Public Health Wales (PHW) explained that there are three key risks leading to some gynaecological cancers - HPV infection, smoking and obesity. The primary focus of prevention is to address these known risk factors.

86. According to PHW, seven per cent of cases of ovarian cancer and 34 per cent of endometrial cancers in Wales could come from being obese or overweight.[55]

87. Dr Sadie Jones, representing the Wales Cancer Research Centre, explained:

> *"Fat cells actually make oestrogen. Oestrogen is our female hormone, and we all have it [...] If you've got more oestrogen compared to your progesterone, it causes the lining of your womb to grow more. Any time you've got more growth or excess growth in an area, the more chance of it going wrong. [...] when you've got rapid growth because of more oestrogen, you're saying, 'Go on, then, have a mistake', and you're promoting it, and that's what fat cells do. They make excess hormones that then drive processes to grow more, which then tempts fate more and, unfortunately, we end up with womb cancer."*[56]

88. The Minister's written evidence states:

> *"Our more general preventative approaches to population risk factors, including on smoking and obesity, will support improved outcomes and reduced incidence for gynaecological cancers."*[57]

[54] A Cancer Improvement Plan for NHS Wales 2023-26
[55] GC13 Public Health Wales
[56] RoP [para 160], 14 June 2023
[57] HSC Committee, 21 September 2023, Paper 1

89. Dr Louise Hanna, representing the Wales Cancer Network Gynaecological Cancer Site Group, told us:

> *"We know the instance of endometrial cancer is going up and up. It's risen by 50 per cent over the last years, and that is linked to lifestyle, in particular obesity."*[58]

90. However, Welsh Government strategies such as the Healthy Weight Healthy Wales delivery plan and the Tobacco control strategy for Wales delivery plan do not include any key deliverables in relation to cancer – there is no specific reference to the impact on cancer prevalence and incidence. Dr Sadie Jones told us:

> *"A lot of promotion has gone on [….]. But I think there is a fundamental problem with the approach that's taken. I think that we underestimate patients' ability to want to understand actually why, so I think a lot of the promotion campaigns are there, 'Obesity causes cancer', and it becomes meaningless. People don't listen to it or engage with it anymore, and actually, when I sit down with a patient in clinic who's got womb cancer, which is caused by obesity in a lot of the cases, they're stunned and shocked and can't believe it, despite the numerous advertising and promotional campaigns that go on."*[59]

Prevention of cervical cancer

91. The World Health Organisation (WHO) states that cervical cancer is preventable and curable, as long as it is detected early and managed effectively. In May 2018, its Director-General announced a global call for action to eliminate cervical cancer:

> *"Achieving that goal rests on three key pillars and their corresponding targets:*
>
> - *vaccination: 90% of girls fully vaccinated with the HPV vaccine by the age of 15;*

[58] RoP [para 377], 27 April 2023
[59] RoP [para 158], 7 June 2023

- *screening: 70% of women screened using a high-performance test by the age of 35, and again by the age of 45;*
- *treatment: 90% of women with pre-cancer treated and 90% of women with invasive cancer managed.*

Each country should meet the 90–70–90 targets by 2030 to get on the path to eliminate cervical cancer within the next century."[60]

92. The only screening programme for the gynaecological cancers is for cervical cancer. According to PHW, most cervical cancers are attributable to Human Papillomavirus (HPV) infection.[61] There are two elements to the prevention of cervical cancer – the HPV vaccination and cervical screening.

HPV vaccination

93. Human papillomavirus infection (HPV infection) is caused by a DNA virus from the Papillomaviridae family. Many HPV infections cause no symptoms and in most people, their body's own immune system will deal with the virus. In some cases, an HPV infection persists and results in abnormalities that could become cancer if left untreated. HPV infection can increase the risk of cancer of the cervix, vulva, vagina, penis, anus, mouth and throat (i.e. nearly all cervical cancer is due to HPV).

94. HPV vaccines can prevent the most common types of infection. Vaccination (recommended between the ages of 9–13 years) plays a vital role in gynaecological cancer prevention.

95. Health boards are responsible for commissioning HPV vaccines and in the most part, are delivered in schools by school nursing teams (usually to girls and boys in Year 9). HPV vaccination is also available for all girls and boys via GPs until the age of 25 (although it is most effective when given before commencement of regular sexual activity). For men who have sex with men, and others who are at similarly higher risk and attending sexual health services, or HIV clinics, the vaccine is available up to 45 years of age.

96. The Minister told us that uptake of the HPV vaccination was impacted during the pandemic due to school closures and access restrictions but health board

[60] World Health Organisation: Cervical Cancer Elimination Initiative
[61] GC13 Public Health Wales

vaccination teams have made significant efforts to recover and increase uptake within the programme.

97. Previously, the HPV vaccination programme was only available to girls but from 2021/22, boys were added to the programme. PHW explain that HPV vaccination is effective at preventing a range of anal, penile and oropharyngeal cancers so can directly benefit all children and can also indirectly reduce exposure of girls to the virus.[62]

98. Jo's Cervical Cancer Trust raised concerns that coverage of the complete two doses of HPV vaccine in girls in the 2021/22 School Year 10 is "worryingly low at 55.1%"[63]. However, PHW explain that there have been changes to the HPV vaccination programme. They say that due to the HPV vaccination programme changing during the COVID-19 pandemic to include all young people, pre-COVID-19 data (2019/20) only includes vaccination uptake by girls, whereas the post-COVID data (2021/22) relates to uptake by all young people.[64]

99. PHW figures show for the academic year 2019-20, 87.3% of girls received dose 1 by 1 April. For the 2021/22 academic year, the figure was 78.9% of all young people (uptake in Wales is broadly comparable to England and Scotland for equivalent age cohorts). In their written evidence, PHW say:

> *"The apparent drop in HPV uptake is predominantly due to lower uptake in boys, while uptake by girls has remained at a similar level pre-and post-COVID-19."*[65]

100. It adds:

> *"There is, however, significant regional variation in vaccination uptake, and the uptake in most areas falls short of the WHO target of 90% uptake for the elimination of cervical cancer, so there is much still to be done."*[66]

101. The Joint Committee on Vaccination and Immunisation (JCVI) has advised that from this academic year (Sep 2023) the HPV programme should be reduced

[62] GC13 Public Health Wales
[63] GC10 Jo's Cervical Cancer Trust
[64] GC13 Public Health Wales
[65] GC13 Public Health Wales
[66] GC13 Public Health Wales

to a single dose, rather than two. PHW says it is aiming to achieve vaccine uptake of over 90% by all children, in line with WHO guidelines, and to reduce inequalities that currently exist.[67]

Barriers to uptake

102. Jo's Cervical Cancer Trust say that vaccine hesitancy and low understanding around the HPV vaccine are widely recognised as barriers to uptake.[68] While Dr Louise Hanna told us that parents may feel that HPV vaccination is not relevant or necessary for their children.[69]

103. The Minister's written evidence states:

> *"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."*[70]

104. According to PHW:

> *"... one of the important messages in vaccination for HPV is that it's not saying that people are sexually active. Also HPV is not a sexually transmitted infection; it is about skin-to-skin contact in the genital area. I do think we have a few myths to bust in that space, and I'd be keen that we keep on reiterating those messages—that it's not necessarily about vaccinating those who are sexually active."*[71]

105. PHW also told us that, "getting boys to take up the vaccination is a little bit more difficult than with girls". They suggested there may be a number of reasons for this:

> *"I mean, the reason is, I guess, personal choice. It may be something to do with parental choice, but I think the most obvious reason is because the risk of cervical cancer doesn't fall on boys themselves, the*

[67] GC13 Public Health Wales
[68] GC10 Jo's Cervical Cancer Trust
[69] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[70] HSC Committee, 21 September 2023, Paper 1
[71] RoP [para 74], 14 June 2023

> *prevention is seen to be indirect. But, actually, there is a direct prevention against infections—oropharyngeal, anal and other HPV infections—in boys. So, there is a good direct benefit as well to boys. I think we can do more to raise awareness of that, but you can imagine that in that age group it's quite difficult to have direct communications around this. But I think the less we make this a myth and the less stigma there is, the more we can have mature conversations about this with this age group."*[72]

106. We also heard that there may be cultural barriers that inhibit people from accessing HPV vaccination or screening. The British Islamic Medical Association (BIMA), told us:

> *"... the association with HPV and that being a sexually transmitted disease arguably results in additional concerns, for example, people are worried that if they are screened and found to be HPV positive, concerns about their sexual promiscuity could be raised. And there are other misguided beliefs, such as, you know, that if they're in a monogamous relationship that will automatically prevent them from developing some of these illnesses."*[73]

Cervical cancer screening

107. The overall aim of Cervical Screening Wales is to reduce the incidence of morbidity and mortality from cervical cancer in Wales. Cervical screening does not detect other gynaecological cancers.

108. The eligible population for cervical screening in Wales are women and people with a cervix aged between 25 and 64 years of age. Those eligible are contacted by letter and requested to book an appointment for a cervical screening (smear) test usually at their GP practice when they are due their next cervical screening test. Patients are also encouraged to contact their GP practice as soon as possible if they have concerns, rather than waiting for their next screening test.

[72] RoP [para 68], 14 June 2023
[73] RoP [para 166], 10 May 2023

109. According to the Minister's written evidence, although the programme was impacted by the pandemic, it was able to recover by December 2021.[74]

110. In January 2022, PHW announced changes to the Cervical Screening Wales programme, in line with UK National Screening Committee recommendations. These changes came about as a result of improvements to the screening test that were implemented in September 2018. This is when PHW implemented Human papilloma virus (HPV) primary testing into the Cervical Screening Wales programme. Wales was the first UK nation to introduce this change. This test is more accurate and effective which means that, if no high-risk HPV is found, the time between appointments has increased from three years to five years. However, where HPV is found then participants are followed up more frequency and invited to screening in a year if no cell changes and if there are cell changes then referral made to colposcopy for review.

111. According to PHW, "the announcement of these changes prompted misunderstanding amongst members of the public" but the resulting public outcry led PHW to launch a communications campaign to help explain the changes. The campaign aimed to rebuild trust in the safety and effectiveness of the cervical screening programme in Wales and to build understanding of HPV and HPV testing.

112. However, the Royal College of GPs (RCGP) note that there is still confusion among the public regarding who is entitled to cervical screening and how often. It says:

> *"Some members of the public believe a smear test is only for people with symptoms, while the differences between the age of patients who qualify for smears and the regularity of the tests between the four nations means that well-meaning publicity often adds to the confusion."*[75]

Uptake of screening

113. PHW report that "nearly 7 out of 10 women invited for screening take up their offer". It's Screening Division Inequities report (2020-21) showed that 69.5% of eligible women attended their cervical screening. Jo's Cervical Cancer Trust report:

[74] HSC Committee, 21 September 2023, Paper 1
[75] GC04 Royal College of General Practitioners

> *"1 in 3 women are not up to date with their cervical screening – with coverage at its lowest level for 20 years - and even lower attendance in some groups."*[76]

114. The Royal College of Nursing (RCN) Wales wants to see targeted action to address inequalities, noting their concerns that young people (aged between 25-29) are less likely to take up the offer of cervical screening than older age groups, and that women living in the least deprived communities are less likely to get screened.

115. The National Federation of Women's Institutes (NFWI) Wales also raise concerns about attendance by young people:

> *"Attendance is lowest amongst those aged 25 and 29 at 63.4% yet cervical cancer is the most common cancer among women under the age of 35."*[77]

Barriers to cervical screening

116. According to research undertaken by NFWI Wales, finding the time to attend routine cervical screening is a key barrier among respondents aged 25 to 49. Other reasons include bad experiences, inconvenient times, worries it would be painful, embarrassment, a physical disability and personal anxieties.

117. 40% of respondents in Wales aged 25 to 49 said that if weekend appointments were available to them, they would be more likely to attend cervical screening and 44% would be more likely to attend cervical screening if evening appointments were offered. 85% felt that text reminders to book their cervical screening appointment would be helpful.

118. It's research also found that 22% of respondents in Wales aged 50 to 64 had not attended cervical screening since the age of 50:

> *"This highlights that uptake of cervical screening amongst people over the age of 50 could be improved by, for example, greater awareness of the risk of cervical cancer and the benefits of screening to this*

[76] GC10 Jo's Cervical Cancer Trust
[77] GC03 National Federation of Women's Institutes

> *demographic and greater awareness about how cervical screening can be made easier after the menopause."*[78]

119. Dr Louise Hanna told us that there are many and varied barriers to women presenting to the health service and there is a lack of data to identify all the barriers within Wales or to quantify the number of individuals affected. She said:

> *"...it is acknowledged that barriers include a past history of sexual assault, or conditions such as vaginismus (uncomfortable spasm in the vagina)... 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."*[79]

Ethnic minority groups

120. According to the Women's Health Wales Coalition (WHWC), it is widely acknowledged that Black and ethnic minority women are less likely to attend cervical screenings than White women:

> *"Research shows that ethnic minority women were more likely to say they'd never attended a cervical screening than White women (12% compared to 8%) while just 70% of Asian women aged 20-65 knew what cervical screenings were for compared to 91% of White women of the same age."*[80]

121. BIMA said there is a significant issue with regard to symptom awareness:

> *"Knowledge is lacking amongst minority communities. The significance of symptoms such as postmenopausal bleeding or post-coital bleeding is not necessarily there and, to a degree, is normalised because the individual is perhaps less keen to report these symptoms, due to a level of embarrassment. There are issues such as language*

[78] GC03 National Federation of Women's Institutes
[79] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[80] GC08 Women's Health Wales Coalition

> *barriers and a need for, for example, transportation to allow these women to access healthcare professionals."*[81]

122. RCGP said greater understanding of cultural belief and practice was needed.[82] While BIMA highlighted the importance of having female healthcare professionals:

> *"because culturally, for many minority groups, they just simply will not speak with a male doctor about these issues, and if there is restricted access to female physicians, then clearly, that can be an issue."*[83]

123. Both BIMA and RCGP highlighted the importance of language and provision of translation facilities. RCGP told us :

> *"I can't stress the importance of having the conversation with the patient not with the translator who's accompanying them, because, many a time, the person who's accompanying the patient—a family member or friend—have translated wrongly. So, using the language line is important, because it's coming from the patient's own words and being translated without bias."*[84]

124. WHWC points to evidence from Race Equality First that language barriers and cultural differences can hinder ethnic minority people's access to healthcare, and highlights the difficulties some individuals can experience in sourcing an appropriate interpreter for medical appointments, with some medical professionals reluctant to use interpreters, preferring family members, including children, to interpret instead.[85]

People with a disability

125. According to the WHWC, two-thirds of physically disabled women have been unable to attend screening. It also says that women with learning disabilities may have difficulties communicating their symptoms and needs or understanding their importance:

[81] RoP [para 165], 10 May 2023
[82] RoP [para 177], 10 May 2023
[83] RoP [para 256], 10 May 2023
[84] RoP [para 252], 10 May 2023
[85] GC08 Women's Health Wales Coalition

> *"... concerningly, '75% of women with a learning disability are 'ceased from recall', meaning they have chosen to remove their names permanently from recall lists inviting them for future cervical screenings."*[86]

126. Cardiff People First told us that providing information about cervical screening in a jargon free, easy-read format would be beneficial for people with a learning disability. It also said that medical professionals need to not treat people with a learning disability as if they are a child:

> *"Treat them with the same respect that you treat all patients and give them time to process everything. If they have got any questions, about how to get the right support for them."*[87]

Self-sampling for cervical cancer

127. Self-sampling is potentially an intervention that will address identified barriers such as embarrassment. Self-sampling is where a person can take a self-collected vaginal sample, in their own home, rather than going to a screening appointment where the cervical screening test is undertaken by a healthcare professional. This self-sample can then be sent to the laboratory to be tested for high-risk HPV virus.

128. NFWI Wales research found considerable support for the option of HVP self-sampling. It found:

> *"43% of those eligible for screening in the 25 to 64 age group and 60% of respondents aged 65 and over in Wales told us that they would in future prefer the option of taking the test at home using a self-sample kit."*[88]

129. Dr Sharon Hillier, PHW, told us:

> *"I'm very optimistic that we'll be looking to self-sampling in the near future for cervical screening. And that will be, again, working with our colleagues across the UK. So, England are undertaking a study*

[86] GC08 Women's Health Wales Coalition
[87] GC19 Cardiff People First
[88] GC03 National Federation of Women's Institutes

> *validate, where they're validating a self-sampling tool, a self-sampling swab, basically, to check how good it is compared to the current practice. So, we're waiting for the outcome of that, and I think that's aimed to be December 2023."*[89]

130. She went on to say that self-sampling might not be as sensitive and specific as a trained professional taking a sample:

> *"So, we'll need to understand that. And also it tests for HPV positive—if somebody is HPV positive, they will have to come back and have a cervical screen, because we need to look at the cells, and you can't do that from a self-sample. So, it's not a panacea that will address everything, but it's going to be a really important part of our toolkit, really, to ensure that those barriers are addressed."*[90]

131. She also pointed out that the cervical cancer screening programme will need to continue for some time to manage the risk and prevalence in the older population of women for whom the HPV vaccination hadn't been available.[91]

132. The Minister confirmed that the Welsh Government would support the introduction of self-sampling if the process was validated:

> *"I think we need to take it very seriously, particularly if that's what helps us to get to the hard-to-reach areas, and I think there's some evidence to suggest that people are more comfortable using that approach. We are financially challenged at the moment, but I think we would definitely need to look at that as a principle, if it looks like it's a successful pilot."*[92]

Our view

133. The main focus of cancer prevention is addressing the known risk factors. There are clear links between certain types of cancer, and smoking and obesity. This is true for some of the gynaecological cancers, and we are concerned that these links are not widely understood by women in Wales. As such, we believe there is a need for further, clearer messaging to better engage the public in the

[89] RoP [para 104], 14 June 2023
[90] RoP [para 106], 14 June 2023
[91] RoP [para 79], 14 June 2023
[92] RoP [para 138], 21 September 2023

promotion of healthier lifestyle choices and the personal benefits associated with these choices, and our recommendation 11 deals specifically with this.

134. We welcome the expansion of the HPV vaccination programme to include boys, although it is disappointing that uptake among boys is considerably lower than girls.

135. We note that, in conjunction with Public Health Wales, the Welsh Government has developed a guide to vaccinations for young people in school years 7 to 11, which includes information on the HPV vaccination offer. We would also like to see this expanded to include information about the changes that happen during puberty/adolescence and what is normal or not.

136. In addition, we think that work is still needed to get the message across that HPV is not a sexually transmitted infection, which may contribute to the lack of take-up by certain groups.

Recommendation 8. The Welsh Government should:

- work with NHS Wales to achieve the WHO's target of 90 per cent uptake of the HPV vaccine; and
- by the end of this Senedd, report on the progress made in relation to meeting the WHO's 2030 vaccination, screening and treatment targets for cervical cancer. And as part of this include data on the incidence of cervical cancer amongst women in Wales and how this has changed during the course of this Senedd.

137. Whilst we understand there are many reasons why women may not attend cervical screening appointments, we support all efforts to make attendance as convenient and comfortable as possible, for example, with evening and weekend appointments being routinely available.

138. We are particularly concerned by the low take-up of cervical screening by ethnic minority women, and believe that further work is needed to increase understanding among these women about the signs and symptoms of gynaecological cancers. There also needs to be a greater understanding among health professionals of cultural belief and practice. We believe this also applies to women with a learning disability.

Recommendation 9. The Welsh Government should work with Public Health Wales to review its equity strategy to:

- ensure everyone eligible for cervical screening has the opportunity to take up their offer; and
- take more targeted action to specifically address those groups of women where take-up of screening is known to be low.

139. Self-sampling is an exciting development that may help address some of the reasons for not attending cervical screening appointments, such as embarrassment. We look forward to the results of the pilot studies in England and welcome the Minister's commitment to support the introduction of self-sampling in Wales, if the process is validated. However, the Welsh Government must act now to ensure the NHS is set up and ready to roll this out as quickly as possible, if approved.

Recommendation 10. The Welsh Government should, in its response to this report, outline what work is being undertaken to ensure that NHS Wales is set up to implement self-sampling at pace, if approved. This should include details of any redirection of resources that might be necessary.

6. Health promotion and symptom awareness

Signs and symptoms

140. The earlier cancer is diagnosed, the easier it is to treat. But recognising the signs and symptoms of gynaecological cancers isn't straightforward because they are easily mistaken for other more common and less serious health problems.

Symptoms of gynaecologic cancers

Abnormal vaginal bleeding or discharge is common for all gynaecologic cancers except vulval cancer.

Feeling full too quickly or difficulty eating, bloating, and abdominal or back pain are common for ovarian cancer.

Pelvic pain or pressure is common for ovarian and uterine cancer

More frequent or urgent need to urinate and/or constipation are common for ovarian and vaginal cancers

141. The Royal College of Nursing (RCN) Wales told us:

> *"... the general public, our female population, need to be more aware of what signs and symptoms they need to look out for."*[93]

142. The Royal College of Obstetricians and Gynaecologists (RCOG) said there is "very poor knowledge of symptoms" particularly of ovarian cancer, with symptoms "commonly attributed to gastrointestinal conditions".[94]

143. Linda Drew, who took part in our engagement work, said she didn't know about ovarian cancer until she was diagnosed:

> *"I saw this list...and I'd literally ticked every one: the bloated stomach, stomach pain, needing to wee more often, extreme fatigue...If I'd seen*

[93] RoP [para 80], 27 April 2023
[94] RoP [para 83], 27 April 2023

> *one of those posters a year before, at least I would have said to my doctor, 'Look, can I have this? I think I've got this ovarian cancer.'"*[95]

144. Linda has been cancer free for 13 years and now takes every opportunity to raise awareness of the symptoms of ovarian cancer. She told us:

> *"... there's no need for so many people to die of ovarian cancer, because there are symptoms. The awareness on risk factors and symptoms is very, very, very low in Wales, and that's for people like myself and health professionals, and it still is, sadly. With ovarian cancer, there is a 98 per cent survival rate if it's caught early, and then I think 4,000 people die a year unnecessarily from it."*[96]

145. We also heard there is a commonly held misconception that cervical screening detects ovarian cancer. Tenovus Cancer Care told us:

> *"... people, feel that, if they've gone for their smear test—the cervical screening—somehow, if they get a 'clear' for that, they haven't got gynae cancer. People are not really aware that the smear test—the cervical screening—does not cover other gynae cancers. And I think that that is something that struck me—that there do seem to be women perhaps who may have some symptoms out there, but they think, 'Oh, I've been for my smear check, so I know it can't possibly be that'."*[97]

146. Target Ovarian Cancer found that 42 per cent of women in Wales wrongly believe that cervical screening detects ovarian cancer. It says:

> *"We need to ensure that the information provided at cervical screening appointments makes clear that it does not test or screen for other gynaecological cancers and include the symptoms of other gynaecological cancers."*[98]

147. Target Ovarian Cancer goes on to say:

[95] Senedd Blog: Gynaecological cancers: Are women being taken seriously?
[96] ROP [para 34], 27 April 2023
[97] RoP [para 58], 27 April 2023
[98] GC06 Target Ovarian Cancer

> *"The most effective way of achieving greater awareness is government funded symptom awareness campaigns. We must ensure that everyone is aware of the key symptoms of ovarian cancer."*[99]

148. Similarly, the National Federation of Women's Institutes (NFWI) Wales would like to see the Welsh Government develop a public awareness raising campaign with the aim of educating the public and health professionals about the subtle signs of ovarian cancer to help ensure that more people are diagnosed early. It says:

> *"As there is no screening programme for ovarian cancer, it is vital that action is taken to educate everyone about the symptoms and to empower women to discuss concerns with their GP."*[100]

149. Public Health Wales (PHW) said that raising awareness about the symptoms of the gynaecological cancers is an important part of cancer prevention and noted that it has previously supported NHS-led campaigns for cancer symptoms targeted at both the public and professionals. However, PHW cautioned that "the sustainability of the public messaging can sometimes be limited". In written evidence, PHW said:

> *"It is very unlikely based on the current available evidence that a specific awareness raising campaign focused on gynaecological cancers would help or be effective."*[101]

150. PHW suggested "a single campaign is not going to be as effective as multiple ongoing, recurrent campaigns".[102]

Our view

151. It is worrying that awareness of the symptoms of the gynaecological cancers, particularly of ovarian cancer, is so low in Wales, with symptoms being commonly attributed to gastrointestinal conditions. While awareness of the cervical screening programme is relatively high, there is a commonly held misconception that cervical screening detects ovarian cancer. There is a danger, therefore, that

[99] GC06 Target Ovarian Cancer
[100] GC03 National Federation of Women's Institutes - Wales
[101] GC13 Public Health Wales
[102] RoP [para 15], 14 June 2023

someone who has symptoms but has had a clear cervical screening test rules out the possibility of a gynaecological cancer.

152. We agree with Target Ovarian Cancer that the information provided at cervical screening appointments should make it clear that it does not test or screen for other gynaecological cancers and include the symptoms of other gynaecological cancers. This information could also be provided when women attend their breast screening appointment.

Recommendation 11. The Welsh Government should, in its response to this report, advise how it is working with Public Health Wales to ensure the information provided at cervical screening appointments makes clear that such screening does not test or screen for other gynaecological cancers, and includes information about the symptoms of other gynaecological cancers. This information should also be provided when women attend their breast screening appointment.

153. More needs to be done to raise awareness of the symptoms of gynaecological cancers. In its response to our report *Waiting well: The impact of the waiting times backlog on people in Wales*, the Welsh Government has already committed to the development of a campaign to both raise awareness of cancer symptoms and encourage people to access health services if they have any concerns or symptoms of cancer. However, we believe that awareness raising about the symptoms of gynaecological cancers specifically is needed.

Recommendation 12. The Welsh Government should work with Public Health Wales, and community leaders and organisations to develop and implement a series of campaigns to raise awareness about the symptoms of gynaecological cancer. These campaigns should:

- be re-run frequently, and should encourage women to seek medical attention promptly if they experience any symptoms;
- include clear messaging to better engage the public in the promotion of healthier lifestyle choices and the personal benefits associated with these choices;
- include consideration of cultural, linguistic and socio-economic factors and be targeted at specific populations and communities that are disproportionately affected by health inequalities.

7. Primary care – health professionals

154. The majority of cancer patients present symptomatically, and so their cancer journey starts with primary care. Primary care professionals such as a GP or nurse within a general practice surgery have a vital role in prompt recognition and rapid referral of suspected cancer.

Awareness of the symptoms of gynaecological cancers among health professionals

155. According to Target Ovarian Cancer, too many women experience misdiagnosis and delays as a result of GPs not being appropriately educated or supported to diagnose ovarian cancer. It found that:

> *"43 per cent of GPs in Wales believe that symptoms only present in the late stages of disease and one quarter of those diagnosed with ovarian cancer report visiting their GP three or more times before being referred for tests."*[103]

156. Target Ovarian Cancer told us:

> *"So, quite often, when women visit their GP, it's an irritable bowel syndrome diagnosis, which shouldn't happen after the age of 50 without ovarian cancer being ruled out; menopause is another one."*[104]

157. It also highlighted its Pathfinder Wales study[105], which 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 cancer.

158. Claire O'Shea received a diagnosis of Uterine Leiomyosarcoma (uLMS) in November 2022. She told us:

> *"Since August 2021, I have struggled to get a diagnosis and timely treatment. When I first presented with symptoms; including a lump in my abdomen, my GP diagnosed me with Irritable Bowel Syndrome, as*

[103] GC06 Target Ovarian Cancer
[104] RoP [para 37], 10 May 2023
[105] Target Ovarian Cancer: Pathfinder Wales

> *a result of a narrow set of questions about my symptoms. This resulted in months of delay."*[106]

159. The Royal College of GPs (RCGP) recognise that "awareness on the topic of gynaecological cancer is not at desired levels" but said:

> *"GPs also do not feel patients presenting with symptoms know that they may be symptoms of these cancers."*[107]

160. The Minister told us:

> *"So, if you think about symptoms, and where they're generally picked up—so, mostly, they're picked up in GP surgeries [ ]. They generally pick up about eight a year, but in order to find those eight, they have to refer literally over 100. So, it's very difficult for GPs, who've got eight minutes to assess, 'Right, do they meet the threshold?' And one of the things we've got now, of course, are rapid diagnostic centres. So, where they don't quite meet the threshold of cancer suspicion, there's a mechanism for them to go down a different route through the rapid diagnostic centres."*[108]

Importance of clinical examinations in primary care

161. In its written evidence, the Royal College of Nursing (RCN) Wales point to a decrease in in-person GP appointments which means women experiencing gynaecological cancer symptoms may not get an internal examination. It says:

> *"The omission of an internal examination has been associated with diagnostic delay in women diagnosed with gynaecological cancer."*[109]

162. It goes on to say that while internal examinations are predominately undertaken by GPs, Advance Nurse Practitioners and consultant nurses working within primary care should be supported to use their skills and competence to

[106] GC11 Claire O'Shea
[107] GC04 Royal College of General Practitioners
[108] RoP [para 78], 21 September 2023
[109] GC16, Royal College of Nursing Wales

deliver these examinations. Advance Nurse Practitioners already complete cervical cancer screening within general practice.[110]

163. The importance of internal examinations was also raised by Dr Louise Hanna, representing the Wales Cancer Network Gynaecological Cancer Site Group. She raised concerns about women not being offered an examination, which meant they weren't being referred:

> *"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. Therefore, an examination is required to demonstrate the appearances of cancer, and there are reports of women not being examined."*[111]

164. RCN Wales highlights research that says that if a clinician does not carry out the examination frequently, the skills or confidence in those skills, may decline along with the ability to distinguish normal from abnormal findings and willingness to undertake the procedure. It calls for health professionals to be able to access training opportunities to ensure they retain their confidence and skills.[112]

165. RCN Wales told us:

> *"... there can be a training issue as well if that GP hasn't done vaginal examinations, because they're taught in their fourth year as a medical student, so it depends whether they've gone on and done any further training."*[113]

Better training for GPs

166. Public Health Wales (PHW) highlighted the importance of raising awareness amongst health professionals:

> *"... because some of the symptoms that people present with are quite non-specific to a particular cancer. So, it's really important that it's seen as part of a suite of diagnostic tools to raise awareness amongst*

[110] GC16, Royal College of Nursing Wales
[111] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[112] GC16, Royal College of Nursing Wales
[113] RoP [para 120], 27 April 2023

> *professionals, so that they can make the right diagnoses, or at least think and consider cancer as a potential differential diagnosis when a patient presents with those symptoms."*[114]

167. The Royal College of Obstetricians and Gynaecologists (RCOG)[115], and Royal College of GPs (RCGP)[116], agreed that increasing education and awareness in primary care is needed.

168. RCN Wales told us about a Welsh pathfinder study in 2016, which was an educational campaign, for GPs, all across Wales to raise awareness amongst patients and GPs:

> *"But that was seven years ago, and I'm sorry to say that I don't think there's been any improvement with regard to GPs understanding those sometimes non-specific symptoms". She called for the campaign to "happen again" stating it needs to be "a regular occurrence."*[117]

169. Dr Aarti Sharma, representing the British Gynaecological Cancer Society (BGCS) agreed that "the education part can't just be a one-off"[118] and needs "somebody taking ownership of making that a regular habit. It needs to be done on a yearly or a two-yearly basis".[119]

170. She went on to say:

> *"I do appreciate GPs have a lot to deal with [...] but it's trying to educate them to pick out what is going to be a problem and refer in an appropriate manner".*[120]

171. The Deputy Chief Medical Officer told us that "GPs are actually, collectively in Wales, doing really well" stating that GPs are generally referring at the rates that National Institute for Health and Care Excellence (NICE) recommends. He said:

[114] RoP [para 9], 14 June 2023
[115] RoP, [para 83], 27 April 2023
[116] RoP, [para 180], 10 May 2023
[117] RoP, [para 85], 27 April 2023
[118] RoP, [para 91], 27 April 2023
[119] RoP, [para 99], 27 April 2023
[120] RoP, [para 91], 27 April 2023

> *"Because if you take the National Institute for Health and Care Excellence guidance for gynaecological cancer, which was first published in 2015, and then again in 2021, it recommends referral, anticipating an ideal conversion rate of 3 per cent from those referrals to a diagnosis of cancer. And that would be the kind of conversion rate to try to diagnose as many early as possible. The rates of GP referrals in Wales have increased enormously in recent years, albeit interrupted by the pandemic. And actually, most health boards now are demonstrating a conversion rate of around 5 per cent. So, for every one person who has got gynaecological cancer, 20 others are being investigated and reassured."*[121]

172. However, Fair Treatment for the Women of Wales (FTWW) told us, "where they exist, NICE or equivalent clinical guidelines are not always followed in Wales, despite their constituting evidence of best practice."[122]

173. While the Cross-Party Group on Women's Health is particularly concerned about the challenges of making a diagnosis of ovarian cancer because, "NICE guidance on this topic is too vague."[123]

174. The Deputy Chief Medical Officer told us:

> *"All GPs will be aware of National Institute for Health and Care Excellence guidance. They may struggle at times to follow it, perhaps. But some of these conditions are very difficult to diagnose clinically. You, I think, know very well that, particularly for ovarian cancer, which has the lowest survival rate, the symptoms are very non-specific. You have no symptoms in the early phase, but then even in the later phase the symptoms are very non-specific—abdominal bloating, urinary frequency, this type of thing—and it's very difficult, I think, then, for a GP sometimes to distinguish what warrants a referral."*[124]

[121] RoP, [para 20], 21 September 2023
[122] GC09 Fair Treatment for the Women of Wales
[123] GC07 Cross-Party Group on Women's Health
[124] RoP, [para 129], 21 September 2023

175. He went on to say:

> *"Clearly, if those symptoms happen in someone over the age of 50, I think that's more of a concern. If they've got major risk factors, as I described, that would be a concern. But this is all quite difficult because so many people present with so many symptoms, and the vast majority of them do not have anything serious underpinning them."*[125]

176. We heard there were also issues with some GPs being able to interpret ultrasound reports. According to Target Ovarian Cancer:

> *"57 per cent said they were confident in interpreting ultrasound reports, and what became very clear is they need more help and support. Lots of them would say they would benefit from a clear descriptive report. So, when the ultrasound comes back, if it's quite tricky to read, they really need that little bit of extra support. Or sometimes, ultrasound reports come back with the finding, 'Ova not visualised', which is not particularly helpful to a GP who's trying to rule out ovarian cancer."*[126]

177. Target Ovarian Cancer told us that more support for GPs is needed, either through access to expertise in secondary care or advice and guidance clinics.

178. Dr Louise Hanna told us:

> *"... we do know that GPs would welcome more support in terms of interpreting CA125, interpreting ultrasounds. And awareness among GPs as well for some of the symptoms of ovarian cancer is less than it is for others. So, support and education for GPs would be important."*[127]

179. Target Ovarian Cancer said that some women who present with symptoms can have "unremarkable test results", and suggested this is an area where GPs could benefit from more support from secondary care:

[125] RoP, [para 129], 21 September 2023
[126] RoP [para 68], 10 May 2023
[127] RoP, [para 326], 27 April 2023

> *"If you have some weird symptoms, but there might not be anything that you can spot in blood tests or in scans that they've had, it's really important that GPs have the systems in place and the support potentially from secondary care to keep up with these patients and follow-up with them, and proactively follow-up with them."*[128]

180. Target Ovarian Cancer refers to this as "primary care safety netting" and says it needs to be more than, 'Come back and see me in 12 weeks or eight weeks if your symptoms are still around', which is what, quite often, people are told:

> *"So, that's why it needs to be proactive from primary care: what can we do in primary care systems to flag-up patients that have these?"*[129]

181. The Deputy Chief Medical Officer told us:

> *"... there is a lot of work being done to support GPs in their individual decision making. So, the NHS is rolling out some decision-support tools, including one called Gateway C—which is quite a flashy-looking app, when I had a look at it yesterday—to help provide information, and in a sense, guidance about when to refer people with sometimes quite vague symptoms."*[130]

Self-referral

182. Cancer Research UK (CRUK) suggested there might be a role for a self-referral pathway, where people can refer themselves for diagnostic testing without seeing their GP:

> *"Some cancer pathways will be more amenable than others; those cancers with red flag symptoms, such as postmenopausal bleeding in some gynaecological cancers, and higher levels of symptom awareness are likely to benefit most."*[131]

[128] RoP, [para 57], 10 May 2023
[129] RoP, [para 59], 10 May 2023
[130] RoP [para 12] 21 September 2023
[131] GC05 Cancer Research UK

183. Dr Louise Hanna said:

> *"On paper, it seems like a really wonderful idea. It would need to be thought through. For one thing, we know that awareness of symptoms among patients could be improved, and so, some patients might not be aware that they would need to self-refer. Also, we do have significant capacity issues across the board within gynaecological cancer, and so, a lot of work would need to be done in order to work out the impact."*[132]

184. BGCS also raised concerns about the capacity within gynaecology departments to manage self-referrals.[133]

185. RCOG said while a self-referral pathway for a very specific symptom like post-menopausal bleeding would take out a potential wait, extra resources would need to come with a self-referral pathway due to the expected increase in numbers.[134]

Our view

186. We know that GPs are under enormous pressure. We understand that recognising the signs and symptoms of gynaecological cancers isn't straightforward because they are easily mistaken for other more common and less serious health problems. But too many women are being sent away with a misdiagnosis, often of irritable bowel syndrome only to find that, sadly sometimes too late, they actually have a gynaecological cancer.

187. NICE guidelines set out the referral criteria clinicians apply when considering risk factors and symptoms for suspected cancer. It is therefore concerning to hear that some GPs may struggle at times to follow it.

188. We appreciate that GPs have a lot to deal with but keeping pace with NICE guidelines is a key part of their role. GPs have a duty of care to their patients, and as such, should be expected to keep up to date with the latest developments in their field. Having said that, we believe it is important that GPs have access to support from secondary care, especially as timely access to gynaecological oncologists can lead to more accurate diagnoses.

[132] RoP [para 322[, 27 April 2023
[133] RoP [para 128[, 27 April 2023
[134] RoP [para 130], 27 April 2023

189. We were interested to hear of the current work being done to raise awareness and support GPs in their decision making, such as the Gateway C app.

Recommendation 13. In its response to this report, the Welsh Government should provide details of any plans it has to evaluate the decision support tool, 'Gateway C', to see what impact it is having on GP referral rates.

Recommendation 14. The Welsh Government should work with the relevant professional bodies and NHS Wales to:

- ensure continuing medical education opportunities have an appropriate focus on gynaecological cancers. This should include a conference/webinar to update GPs on the latest guidelines and diagnostic techniques focused on gynaecological cancers to take place by the end of March 2024;
- ensure the clinical guidelines that outline the symptoms and risk factors associated with gynaecological cancers are clear and being implemented. This should include an audit of GP referrals and patient outcomes related to gynaecological cancers to provide feedback to GPs to help them improve their diagnostic skills;
- provide GPs with support from secondary care to assist them in the assessment and referral of patients with potential gynaecological cancer symptoms. For example, telemedicine solutions that allow GPs to consult with specialists remotely (this can be particularly useful for GPs in rural or underserved areas).

8. Emergency presentations

190. While many cancer diagnoses follow a GP or screening service referral, Cancer Research UK (CRUK) say around 17% follow an emergency presentation. We heard that many women are diagnosed with a gynaecological cancer in hospital, often after attending A&E. These women often present with late-stage cancer symptoms.

191. We invited the Royal College of Emergency Medicine (RCEM) to take part in our inquiry. However, it felt the issues being considered were outside its remit:

> *"Although gynaecological cancers may on occasion present to the Emergency Department, the management of these conditions is not usually handled by emergency medicine doctors, so we do not feel we are best placed to answer these questions."*[135]

192. Dr Louise Hanna, representing the Wales Cancer Network Gynaecological Cancer Site Group, said that "we're never going to completely get rid of emergency presentations, because there will be a few, but I think there are too many as it is".[136]

193. Professor Tom Crosby, Wales Cancer Network (WCN), agreed that "emergency presentations of cancer for Wales and the UK is far, far too high".[137] He said that the increase in number of emergency presentations is down to delays in accessing diagnostic tests and difficulties in getting GP appointments:

> *"We've done international cancer benchmarking partnership exercises to look at Wales compared to the UK, compared to other countries, and we know that the pathways after patients present to the healthcare system—usually GPs—are too long; we know that patients, whilst waiting after having seen a GP, have to then sometimes go to A&E because symptoms progress."*[138]

[135] HSC Committee, 14 June 2023, Paper 7.2
[136] RoP [para 369], 27 April 2023
[137] RoP [para 373], 27 April 2023
[138] RoP [para 371], 27 April 2023

194. Professor Dyfed Wyn Huws, Director of the Welsh Cancer Surveillance and Intelligence Unit (WCSIU), told us:

> *"... there is a trend in Wales for cancers to be diagnosed late and there are a number of reasons for that. Also, there is a tendency for cancers to be diagnosed in emergency departments, either being sent in as an emergency by the GP or presenting in A&E."*[139]

195. According to the Royal College of Obstetricians and Gynaecologists (RCOG):

> *"... A&E diagnosis is really a failure of our healthcare system in diagnosing cancer. It's acceptable, and obviously, people do; there will be patients coming into the pathway through A&E, but that shouldn't be as significant a number as it is, and it's a measure of accessing healthcare."*[140]

Our view

196. We understand that there will always be a certain number of cancer cases that are diagnosed through emergency admissions. However, in Wales this figure is unacceptably high.

197. The number of women being diagnosed with a gynaecological cancer following an A&E admission suggests that something is going wrong in primary care. The failure to identify those women in primary care settings raises questions about the effectiveness of the system to detect symptoms early, as well as the referral processes.

198. There needs to be a better understanding of whether there are particular types of gynaecological cancer that GPs are having difficulties identifying, meaning women are presenting late with symptoms or via A&E. This information can influence what improvement support is needed.

Recommendation 15. The Welsh Government, in conjunction with the Wales Cancer Network, should commission an urgent review of the incidence, trends and high-risk populations in relation to emergency presentations with a gynaecological cancer, broken down by each of the gynaecological cancers. This review should include access to primary care, symptom recognition amongst GPs,

[139] RoP [para 55], 29 June 2023
[140] RoP [para 150], 27 April 2023

misdiagnosis and communication and referral processes. The findings should be shared with the Committee within six months of the publication of this report.

9. Treatment

Waiting times for treatment

199. Health boards are expected to comply with the Welsh Government target for 80 per cent[141] compliance for patients to start their first definitive treatment within 62 days of the point of suspicion of cancer by 2026 (the single cancer pathway (SCP)). The Planned Care Improvement and Recovery Team agreed a milestone with Health Boards of 70 per cent compliance by March 2023 but this was not achieved.[142]

200. The Minister told us:

> *"I've been clear with the NHS that, actually [ ] when it comes to cancer, right, the 62-day limit—. I'm more worried about the people who've breached the 62-day limit, right, and I want those people treated, because they're waiting a long time; they're waiting longest. But treating them is not going to help me with my targets, because I've breached those targets, so—. But I don't care, frankly, because I want those people seen. So, I've made it very clear that they have to be seen before, which means that we are less likely to hit our target. But I think that is where it should be, and I'm happy to defend that position."*[143]

201. According to the Minister's written evidence:

> *"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*

[141] A Cancer Improvement Plan for NHS Wales 2023-26
[142] NHS Wales Waiting times – termly monitoring report, June 2023
[143] RoP [para 88], 21 September 2023

> *confirm which types of gynaecological cancer may be contributing most to those increases."*[144]

202. The Welsh Government's plan 'Transforming and modernising planned care and reducing NHS waiting lists in Wales'[145] sets out the timelines for tackling the increased waiting times for cancer diagnosis and treatment. Data from January 2023 showed that performance against the SCP for gynaecological cancers was poor. It was only 34%, which is significantly below the SCP target.

203. Professor Tom Crosby, Wales Cancer Network (WCN), noted "we do have a major problem at the moment with demand generally outstripping capacity in the system. And this is true across the pathway for gynaecological cancers".

204. The Minister told us:

> *"But what I think you're focused on is, in particular, gynaecological cancers, and the statistics in relation to that are not where we want them to be. One of the things that I've done is to ask the NHS Wales Executive to focus on the three cancers where we're not getting the kinds of results that we should be getting—one is gynaecological, one is urology and the other is upper gastrointestinal."*[146]

Access to new cancer drugs and treatments

205. Wales has three specialist cancer centres – in Swansea, Cardiff and North Wales. Dr Louise Hanna, representing the Wales Cancer Network Gynaecological Cancer Site Group, told us that to provide the best care to women, NHS Wales needs to attract "world-class specialists". She said new technologies, facilities and infrastructure for research, as well as the prompt implementation of new innovations are all key:

> *"... there are some treatments where we have lagged behind the rest of the UK in terms of implementing them. I'm talking about new cancer drugs, robotic surgery, that kind of thing. In terms of research and innovation, we've now got the multidisciplinary research group in Wales for gynaecological cancer, which is taking things forward, but*

[144] HSC Committee, 21 September 2023, Paper 1
[145] Our programme for transforming and modernising planned care and reducing waiting lists in Wales, April 2022
[146] RoP [para 7], 21 September 2023

> *there's an awful lot more that we could do to actually make it more attractive and to retain people."*[147]

206. We heard that some new cancer drugs and treatments have taken longer to introduce in Wales. The Royal College of Nursing (RCN) Wales said "we always seem to be on the back foot in Wales".[148]

207. The drug Bevacizumab (also known by its trade name Avastin) was specifically discussed. RCN Wales advised that Bevacizumab was first given its licence and made available to patients in England with a metastatic cervical cancer in 2014. In Scotland, it was able to be accessed seven years ago.

208. RCN Wales told us:

> *"So, we are now nine years behind, and we've only just been able to give this drug to our metastatic cervical patients in the last six months, because the funding wasn't available."*[149]

209. RCN Wales went on to say "this isn't the first time", referencing a chemotherapy drug called Paclitaxel (which had only been available to patients in some parts of Wales) and says it continues to be a problem:"[150]

> *"... there's another drug as well, which is one of the immunotherapy-type drugs, pembro. Pembrolizumab is also a drug that's been available for metastatic cervical cancer patients in England, and we're hopefully going to have the final sign-off within the next six to eight weeks, to allow our patients access to it."*

210. The British Gynaecological Cancer Society (BGCS) told us "this kind of disparity should not happen". She said that clinicians have to resort to Individual Patient Funding Request (IPFR) to try to get funding for their patients:

> *"We have had clinicians [ ] who are spending time filling out these IPFR forms to get funding for these patients to be able to get the drug. We've done that so many times for so many patients, and we don't know whether it will be approved or not, so we may make patients*

[147] RoP [para 275], 27 April 2023
[148] RoP [para 201], 27 April 2023
[149] RoP [para 197], 27 April 2023
[150] RoP [para 201], 27 April 2023

> *wait for two to four weeks just to find out whether it will be approved or not."*[151]

211. BGCS went on to say it was aware of patients with relatives in England who had used their postcode to receive treatment.[152]

212. The Deputy Chief Medical Officer told us he was not aware of any specific examples in relation to gynaecological cancer:

> *"There is a drug for prostate cancer, the name of which I think—they're all a jumble of consonants. I think I forget the name. But that's one that's come to my attention. But I think, increasingly, as these approvals come for certain patients with certain clinical and often biochemical or histological criteria, then it's great, because this is precision medicine starting to be seen, that, actually, we would expect these drugs, when they're targeted at the right people, to be more effective. These do represent new ways of working, and they do bring with their implementation practical challenges."*[153]

213. Target Ovarian Cancer told us that generally speaking, once treatments are recommended by NICE they are available in Wales "pretty much simultaneously".[154]

214. Dr Louise Hanna explained the reasons for these different viewpoints. She said the drug Bevacizumab was licensed for a specific dose, and wasn't NICE approved for the lower dose. However, it was funded in England through the Cancer Drugs Fund, which Wales doesn't have. The All Wales Medicines Strategy Group (AWMSG) looked at it but decided it wasn't cost-effective:

> *"It was only when the price came down that it was then deemed to be cost-effective and it was then approved."*[155]

[151] RoP [para 207], 27 April 2023
[152] RoP [para 205], 27 April 2023
[153] RoP [para 149], 21 September 2023
[154] RoP [para 103], 10 May 2023
[155] RoP [para 354], 27 April 2023

215. Professor Iolo Doull, Chair of the AWMSG explained the different routes for medicines to go through to be approved in Wales.[156] He argued "potentially, Wales has faster access to new medicines than the rest of UK".[157]

Implementation of new NICE-recommended cancer drugs

216. Professor Tom Crosby focused on the implementation challenge some health boards face when new pathways need to be set up to support access to new cancer drugs and treatments. It can often result in extra work for some services that are already under considerable pressure – for example, some new cancer drug treatments rely on hospital pharmacy services and nurses to assess and administer the drug.

217. Dr Louise Hanna explained:

> *"You need to get the chair space if it's given intravenously, you need to have the clinic space and the workforce to see the patients in clinic and to assess them for toxicities, you have to have the ability to manage those toxicities, and the funding for that doesn't necessarily come with the drug. And so you can introduce drugs within your existing capacity, but, then, at some point, you then exceed that capacity and then the system then starts to fall over and to creak."*[158]

218. The Deputy Chief Medical Officer also highlighted the implementation challenge that some of these new medicines bring with them:

> *"So, some of the new medicines require whole-scale changes in the clinical pathway, sometimes more testing by pathology services, and they naturally take longer to implement. So, the drug is available, but actually not rolled out because of the implementation challenges. And some health boards are struggling to meet those implementation challenges. It requires whole new pathways to be set up; it's extra work for some services that are already under considerable pressure. So, we do understand the challenge, but still,*

[156] RoP [para 225], 14 June 2023
[157] RoP [para 224], 14 June 2023
[158] RoP [para 355], 27 April 2023

> *the commitment is there to deliver on NICE-recommended medications."*[159]

219. Professor Crosby told us:

> *"We've got lots of really good drugs coming through with immunotherapies et cetera but we are really, really drowning in terms of demand in out-patients in terms of assessing these patients."*[160]

Secondary care – treating women with dignity and respect

220. There is no excuse for not treating women with dignity and respect, no matter how much pressure a service is under. In her video evidence, Judith Rowlands talked about her experience on a mixed sex ward:

> *"She came and she lifted my nightie. She didn't put the curtains round or nothing. She just lifted my nightie and she said, 'Oh, you're fine now—you're perfectly fine'."*[161]

221. This is simply not acceptable.

Our view

222. It is disappointing that performance against the single cancer pathway is so poor for gynaecological cancers. We are therefore pleased that the Minister has identified gynaecological cancers as one of her priority areas. The importance of transparent reporting to the public and stakeholders is key.

223. Given this is one of the Minister's priorities, we believe she should regularly publish data on key performance indicators such as a waiting times, patients outcomes and access to care. We also ask the Minister to consider keeping this as a priority for the next financial year, given that we are only now starting to see small improvements.

Recommendation 16. The Welsh Government should clearly outline its ongoing commitment to prioritising gynaecological cancer and to providing the essential attention and resources required to positively impact women's health. To ensure

[159] RoP [para147], 21 September 2023
[160] RoP [para 363], 27 April 2023
[161] RoP [para 15], 10 May 2023

continual improvement in gynaecological cancer care, the Welsh Government should work with the NHS Executive to consistently publish key performance data for the cancer interventions (such as waiting times, patient outcomes, and access to care), promoting transparency and better women's health outcomes.

224. We heard a lot of frustration among clinicians around perceived delays in accessing new cancer drugs. We are satisfied with the reassurance from the Deputy Chief Medical Officer and All Wales Medicines Strategy Group that NICE-recommended cancer drugs are available within 60 days of approval so that women in Wales diagnosed with a gynaecological cancer can benefit from them once they are licenced. However, we are concerned to hear that some health boards are struggling with implementation challenges.

Recommendation 17. The Welsh Government should work with the All Wales Medicines Strategy Group and relevant professional bodies to:

- improve understanding of the challenges of implementing new NICE recommended drugs to help alleviate some of the frustrations and misunderstanding there is among healthcare professionals;
- address some of the challenges facing health boards in implementing new NICE-recommended drugs, setting out a plan for how they will ensure there will be sufficient capacity to allow women in Wales, diagnosed with a gynaecological cancer, to benefit from prompt access to these new treatments. This should include an analysis which new cancer drugs for treating gynaecological cancer are likely to be approved in the short to medium term.

225. While we know the NHS is under extreme pressure, there is no excuse for not treating women with dignity and respect. We were particularly concerned by Judith Rowlands' experience on a mixed sex ward. No woman should be treated this way by a health professional.

Recommendation 18. The Welsh Government should write to all health boards to remind them of their duty to ensure that all patients are treated with dignity and respect.

10. Cancer workforce

226. There are capacity issues across all the cancers, and gynaecological cancer services are affected by that. This includes a shortage of radiologists, pathologists, oncologists and nurses. Dr Louise Hanna, representing the Wales Cancer Network Gynaecological Cancer Site Group, described a bleak picture, saying "we've got pressures on theatre space, we've got pressures on radiotherapy, on chemotherapy".[162]

227. The British Gynaecological Cancer Society (BGCS) outlined a similar picture:

> *"There is a shortage of pathologists, there's a shortage of radiologists; this is nationwide, but we are in a very difficult situation with that in Wales as well. And unless there is that influx of funding, the improvement of infrastructure, and the people who are going to provide that care, there isn't a straightforward answer."*[163]

228. The Royal College of GPs (RCGP) said improving workforce retention and recruitment is important, "people are leaving in droves".[164] On top of that, there appears to be poor workforce and succession planning across NHS Wales. The Wales Cancer Network's Gynaecological Cancer Site Group has undertaken a national peer review of gynaecological cancer services, which highlighted inequities including the need for acute oncology services and cancer nurse specialists.[165]

229. Dr Louise Hanna told us:

> *"... we don't know what the gynaecological cancer workforce is in Wales, so how can we know what we need to do if we don't know where we're starting?"*[166]

230. In response to a letter from the Committee dated 17 May 2023[167], Health Education Improvement Wales (HEIW) said:

[162] RoP [para 302], 27 April 2023
[163] RoP [para 193], 27 April 2023
[164] RoP [para 198], 10 May April 2023
[165] GC15 Wales Cancer Network's Gynaecological Cancer Site Group
[166] RoP [para 380], 27 April 2023
[167] Letter to Health Education and Improvement Wales, 17 May 2023

> *"a pathway workforce planning methodology for Health Boards to use which supports implementation of the Single Cancer Pathway and a guide and resources are now available."*[168]

231. HEIW said that they have been looking at urology and lung cancer but had not done any specific work in relation to gynaecological cancers although "this is something that we can consider as part of the forward work programme".[169]

232. The Minister told us that it is difficult to know exactly what the workforce is, because they work across various disciplines:

> *"If you think of the diagnostic pathway, for example, if you put someone into a diagnostic centre, it's not just diagnostics for cancer; they do diagnostics for lots of different other things too. Therefore, you'd have to ask whether they count as part of the cancer workforce or not. That's why it's difficult to say, 'Such and such a number working directly on cancer.'"*[170]

233. The Deputy Chief Medical Officer added that the need to build oncology capacity was acknowledged, and health boards have agreed with HEIW and the Minister that there would be an increase in the training programmes of four extra training places per year for clinical oncology, and three in medical oncology:

> *"So, between 2025 and 2030, there will be 35 extra oncologists coming out of the training scheme, and we've also increased numbers for clinical radiology as well because that's been a pressure area. We can't easily say how many people are working specifically in gynaecological cancer because most people are working in a wider sphere, but we are trying to promote resilience across the whole pathway in workforce terms."*[171]

234. The Minister confirmed that it is up to health boards to assess their staffing needs, and request that HEIW make provision for it:

[168] Letter from Health Education and Improvement Wales, 9 June 2023
[169] Letter from Health Education and Improvement Wales, 9 June 2023
[170] RoP [para 63], 21 September 2023
[171] RoP [para 66], 21 September 2023

> *"HEIW then looks at what's required across the whole of Wales, and it's they who decide. That's the system. There are occasions when I can tell HEIW, 'No, I want you to focus a little more on a certain area.' For example, I asked them last year to focus on training more people involved in dentistry. So, it's possible to do that, but I don't want to intervene too much, because we do have a system in place that responds to what's identified as local need by the health boards."*[172]

Cancer nurse specialists

235. Gynaecological cancer nurses are employed by NHS Wales, Macmillan Cancer Care and other third sector providers. To become a gynaecological cancer nurse, an individual must be registered on the Nursing and Midwifery Council (NMC) register having completed an undergraduate degree in either adult, mental health, child or learning disability nursing.

236. Providing women with high quality care for gynaecological cancers requires an adequately staffed, motivated, well-trained and well supported workforce. The Women's Health Wales Coalition (WHWC) said "there's an urgent need for more specialist cancer nurses".[173]

237. According to Royal College of Nursing (RCN) Wales, there is currently no way to identify how many gynaecological cancer nurses are employed in Wales, as the Welsh Government do not publish this information. It says:

> *"This is crucial information for workforce planning and ensuring Wales can meet public demand now and in the future."*[174]

238. HEIW confirmed "regrettably" this was the case. However, it said:

> *"We are aware of a recent piece of work conducted by the Wales Cancer Network which attempted to capture data on the size and shape of the specialist workforce through a census. The dataset is not comprehensive, but it does provide a baseline provision and indicates that there are around 22 gynaecological cancer specialist nurses working in Wales currently. Given that one HB [health board] has not*

[172] RoP [para 68], 21 September 2023
[173] GC08 Women's Health Wales Coalition
[174] GC16 Royal College of Nursing Wales

> *submitted data to the census, this under-represents the true position."*[175]

239. In its report, Cancer Nursing on the Line[176], Macmillan Cancer Care said that the cancer nursing workforce in Wales has been under huge strain since long before the start of the pandemic. Previous analysis published by Macmillan has demonstrated the impending capacity crisis in cancer nursing:

> *"Our cancer workforce census published in 2018 highlighted that 74% of breast and 50% of gynaecology specialist cancer nurses were over the age of 50,which means they are often within 10 years of retirement. It also highlighted that Wales faced a higher vacancy rate for specialist cancer nursing posts than the UK-wide rate for those working in human health and social work."*

240. This point was reiterated by RCN Wales who told us:

> *"... in the next five to eight years, the majority of the workforce—the gynae cancer specialist nurses—will have retired."*[177]

241. HEIW told us that approximately 44 per cent of the gynaecology specialist cancer nursing workforce are over the age of 50. RCN Wales said:

> *"I've got expertise in gynae cancers because I've been doing it a very long time. If we don't look at recruitment and funding for succession planning, all your expertise will be gone in a few years' time, so rather than the patients having an expert as their key worker, they will have a novice."*[178]

242. We heard that HEIW will be working collaboratively with the Wales Cancer Network (WCN) over the next two years to develop a competency framework for both nurses and allied health professionals, which will include work to understand

[175] Letter from Health Education and Improvement Wales, 9 June 2023
[176] Cancer Nursing on the Line: why we need urgent investment across the UK, September 2021
[177] RoP [para 170], 27 April 2023
[178] RoP [para 170], 27 April 2023

the future demand and capacity needed across a number of areas including the surgery and oncology cancer nursing workforce areas.[179]

Gynaecological cancer consultants

243. BGCS told us there will also be a shortage of gynaecological cancer consultants:

> *"We were made aware that there were 12 gynae oncology posts that were coming out—consultant posts—overall in the UK, and we know that there are only four people finishing their training. So, how do you use four people to fill 12 posts? It's the same sort of issue in Wales, but this is unfortunately a UK-wide issue."*[180]

244. Professor Tom Crosby, Wales Cancer Network (WCN), said whilst it is usual to look to HEIW to create a workplace plan, health boards must take responsibility for "creating the capacity to train people for the future". He's concerned that because health boards are held to account for their current performance, they will resort to outsourcing, insourcing and other mechanism to maintain their performance. But whilst "buying in the specialist workforce helps in the short term" it provides no resilience in the medium and longer term.[181]

245. Data on the number of consultant gynaecological oncologist posts, the number of vacant posts, and relevant number of consultant training posts is held by health boards in Wales.

Radiology

246. There is a shortage of radiologists in Wales, which means there are delays in obtaining scans, as well as delays in reporting scans which contributes to longer waiting times.

247. According to the Royal College of Radiologists, "workforce growth is not keeping pace with demand". It says:

> *"Put quite simply, we do not have the workforce to manage the level of demand we are seeing today. In 2022, as waiting lists for scans rocketed, the clinical radiology (CR) workforce grew by just 3%. While*

[179] Letter from Health Education and Improvement Wales, 9 June 2023
[180] RoP [para 186], 27 April 2023
[181] RoP [para 395], 27 April 2023

> *the number of consultants joining the workforce has remained in line with the five-year average, the number of consultants leaving is considerably higher. Concerningly, 76% of consultants (whole time equivalent (WTE)) who left the workforce in 2022 were under the age of 60.*
>
> *There is an urgent need to invest in the radiology workforce with a targeted workforce plan."*[182]

Our view

248. We were deeply concerned to discover that there is no clear picture of the cancer workforce in Wales. We know there are shortages across all specialties, including radiologists, pathologists, oncologists and nurses. While we understand that people work across different specialties and these are not just cancer-related, we do not accept the Minister's suggestion that this means the cancer workforce cannot be defined. Without that clear baseline, how can adequate future provision be planned for and provided.

249. We know that around 44 per cent of the gynaecology specialist cancer nursing workforce are over the age of 50. We also know that Wales has the highest proportion of pathology staff aged 55 or more. We therefore ask the Welsh Government to provide details of the planning taking place to fill these posts in the future.

Recommendation 19. The Welsh Government should, within 6 months, undertake a comprehensive review of the gynaecological cancer workforce in Wales, identify where there are, or are likely to be, shortages, and take steps to recruit into those posts. It should report its findings to us on completion of the review.

Recommendation 20. The Welsh Government should instruct Health Education and Improvement Wales to include gynaecological cancers in its work on pathway workforce planning methodology.

[182] Royal College of Radiologists, Clinical Radiology Workforce Census 2022

11. Information and intelligence

Lack of data and intelligence

250. The Cancer Improvement Plan for NHS Wales 2023-26[183] states there is "a responsibility on all the organisations in Wales that collect, analyse and publish data on cancer patients and pathways to ensure that timelines, quality and accessibility of their data is maximised".

251. However, a number of respondents raised issues around data. Tenovus Cancer Care was clear that "data is a massive issue".[184] Dr Louise Hanna representing the Wales Cancer Network Gynaecological Cancer Site Group agreed "more" and "accurate" data is needed.[185] While Dr Sadie Jones, representing the Wales Cancer Research Centre noted:

> *"At the moment in Wales, we do not know our outcomes specific for our gynae cancers, and we do not know where we're going wrong and what could be improved. So, we need to know that so that we can then drive things better for the future."*[186]

Disaggregated data

252. Data on the gynaecological cancers is currently pooled together. Target Ovarian Cancer explained that the five gynaecological cancers have very different diagnosis and treatment pathways, and so when they are collated together, it is difficult to identify where pinch points are in the system and therefore the actions needed to make improvements.[187]

253. Dr Louise Hanna explained:

> *"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*

[183] A Cancer Improvement Plan for NHS Wales 2023-26
[184] RoP [para 84], 10 May 2023
[185] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[186] RoP [para 276], 14 June 2023
[187] RoP [para 83], 10 May 2023

> *individual gynaecological cancer types for tracking purposes would allow a focussed approach with each cancer pathway."*[188]

254. We were told that all the gynaecological cancers are listed separately on the cancer database. Helen Thomas, Chief Executive of Digital Health Care Wales (DHCW) confirmed "the data is collected via the cancer tracker".[189] However, senior clinicians and cancer charities have all insisted "routinely available data on an all-Wales basis is not disaggregated by cancer type".[190]

255. Dr Louise Hanna told us:

> *"Clinicians are often reliant on reporting their own experiences without the data to back up their assumptions".*
>
> *"... we're relying on personal audits, actually trawling through individual data to try and get information."*[191]

256. However, it became clear during the course of the inquiry that data on cancer patients is collected and held by a number of different organisations, with varying roles and responsibilities. As a result, there are cancer data silos leading to confusion and frustration.

257. Professor Dyfed Huws, Director at the Wales Cancer Intelligence and Surveillance Unit (WCISU) helped to clarify the situation. He said WCISU's role is primarily "to collect information about every case of cancer in the Welsh population".[192] He explained that every year the unit publishes official figures regarding the incidence of all cancers, survival rates and the death rates from those cancers (albeit there are significant delays in publishing the data).

258. It became clear that WCISU publishes official figures regarding the incidence of all cancers, survival rates and the death rates from those cancers, which it shares with the Wales Cancer Network and health boards. The raw data that's analysed by WCISU is provided to them by DHCW. But the missing part is analysing the data to enable service change.

259. The Deputy Chief Executive of NHS Wales told us:

[188] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[189] RoP [para 73], 29 June 2023
[190] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[191] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[192] RoP [para 11], 29 June 2023

> *"We've got all the data; what we're not good at is pulling it out into visible support mechanisms that help us then start to identify the problems."*[193]

Protected characteristics

260. To address health inequalities, the Welsh Government must publish data that can highlight disparities and ensure all populations receive equitable care. However, we heard there were issues around data not being disaggregated by protected characteristics. According to the Women's Health Wales Coalition (WHWC):

> *"It is also that this data can also be broken down and analysed by different characteristics, geography, and socioeconomic background in order to identify and respond to inequalities in outcomes and experience."*[194]

261. While evidence from Tenovus Cancer Care states:

> *"Reports from the USA indicate that black women are slightly less likely to get gynaecological cancer but 1.3 times more likely to die of it. We do not know if that is the case in Wales because we do not collect ethnicity data through the cancer informatics system. The new system, now available across the NHS, and in use by healthcare professionals, has the technological means of collecting ethnicity data, but we understand that that is a low priority, and unlikely to be acted upon for some time."*[195]

262. It wants to see this rectified, and the collection of ethnicity data prioritised by the NHS.

National ovarian cancer clinical audit

263. The last British Gynaecological Cancer Society (BGCS) supported audit looking at outcomes of ovarian cancer only looked at the data for NHS England. This was because the Welsh and English data systems did not align, so the data

[193] RoP [para 115, 21 September 2023
[194] GC08 Women's Health Wales Coalition
[195] GC14 Tenovus Cancer Care

couldn't be pulled in an automated way as it was being in England. The Royal College of Obstetricians and Gynaecologists (RCOG) told us:

> *"We were very happy to link into that, but we failed for several years and only recently have been able to secure funding to have our own audit, which will, in fact, probably end up being better than the automated English audit, but it's taken several years to do so."*[196]

264. Target Ovarian Cancer was optimistic that "Wales, along with England, are going to have some really good data on ovarian cancer once the audit's out".[197] However, Tenovus Cancer Care suggested that:

> *"... we're probably going to find that there's a challenge in terms of our own data to be able to input into that audit... we're going to be challenged in terms of not having that data collected in the first place."*[198]

265. Dr Sadie Jones, representing the Wales Cancer Research Centre also referred to the BGCS audit, highlighting that:

> *"They have a benchmark understanding of the state of play in England, and it was a bomb, it really was, this understanding of the heterogeneity, the differences that existed, and it has really promoted lots of change to go on. We don't have that data for Wales; that wasn't done in Wales. The funding didn't reach us for us to do that. However, we have conducted our own piece of work to look at it, and we have all of that data available in my hands, but because we have not got the resource and the ability to analyse it and look into it, we've not been able to have that same impact going forward."*[199]

266. Following her evidence to Committee (above), DHCW told us they were going to approach Sadie Jones to help her analyse the data.[200]

[196] RoP [para 166], 27 April 2023
[197] RoP [para 83], 10 May 2023
[198] RoP [para 84], 10 May 2023
[199] RoP [para 148], 14 June 2023
[200] RoP [para 29], 29 June 2023

Cancer Network Information System Cymru (CaNISC)

267. We heard that a priority for NHS Wales in terms of cancer data has been "replacing the legacy digital cancer platform"[201] the 'Cancer Network Information System Cymru' (CaNISC) with the new Cancer Informatics System (CIS) which is being rolled out in phases.

268. We were told that there is no doubt the new system is needed. Richard Peevor, representing the Royal College of Obstetricians and Gynaecologists (RCOG), described the NHS Wales' IT system as "archaic", and said "we can't make any more amendments without the risk of the system wholly crashing".[202]

269. DHCW said Velindre cancer centre has been using the new system since November 2022 but it hasn't been rolled out to all health boards yet. Helen Thomas said that she wasn't able to tell us when she expects the roll-out to be completed:

> *"We are working with the Welsh Government and the health boards in terms of the longevity of funding. We've got digital priority investment fund funding to support this until the end of March next year. There will be more work that we'll need to do, and, clearly, we will need sustainable funding in place, and we're working with the system on that, because the last thing I want is that we would have another CaNISC, where you have a system that's not being actively developed and becomes obsolete and unsupported."*[203]

270. However, some concerns were raised with us that the new system isn't fit for purpose. Richard Peevor highlighted problems accurately documenting the correct stage for a patient in their cancer journey which means "we don't have the outcomes to compare with international data to see are we doing well in Wales, are we on par or are we actually struggling."[204]

271. Professor Tom Crosby, Wales Cancer Network (WCN), agreed "we're not able to do really key things". He told us there are significant limitations to the new system:

[201] A Cancer Improvement Plan for NHS Wales 2023-26
[202] RoP [para 167], 27 April 2023
[203] RoP [para 66], 29 June 2023
[204] RoP [para 241], 27 April 2023

> *"I cannot also tell you routes to referrals for emergency diagnoses as opposed to GP referrals, as opposed to routine referrals, et cetera, and I don't know stage of diagnosis. And to be honest, we knew those seven years ago, and we don't know them now."*[205]

272. During the evidence session on 29 June, DHCW said they would discuss Professor Crosby's concerns with him. They subsequently provided the following information to us:

> *"My understanding is that Canisc was previously able to support capture of cancer staging information, however, as those staging algorithms were updated or changed, the Canisc system was unable to be updated as no developments were possible given the fragility of the system.*
>
> *The new solution will now support the capture of staging information as part of the Cancer dataset collections being implemented. The new system already supports the capture of routes to diagnosis, tumour subtype and stage at diagnosis for gynae Cancers as part of the newly developed Cancer dataset collections that have been deployed to all Health Boards, timelines for adoption and implementation of the new solution by Health Boards to be agreed by 31st August 2023."*[206]

Our view

273. We recognise the important work of the Wales Cancer Intelligence and Surveillance Unit but we are concerned about the timeliness of official cancer statistics produced by the unit, particularly as the data available to us during our inquiry was for the period 2017-19.

274. We are pleased to have confirmation from the Minister that cancer survival and mortality figures, to include 2020, will be published in October and December 2023 respectively. We are also pleased to see the incidence figures published in August. However, we are not sufficiently reassured by the Minister's

[205] RoP [para 342], 27 April 2023
[206] PTN 16, 21 September 2023

response that the WCISU is adequately resourced to validate these statistics in a timely way.

275. We understand that NHS Wales collates a wealth of internal management data that is used to oversee cancer service delivery. But we are concerned that this management data isn't being shared with senior clinicians who have told us they are "trawling through individual data to try and get information"[207]. It is concerning to hear from senior clinicians that they don't have access to comprehensive data that enables them to make informed decisions about cancer prevention, treatment and priorities. The Welsh Government must support health boards to make better use of this management data.

276. The Deputy Chief Executive of NHS Wales told us that work is being done to disaggregate performance data so that it can be broken down by type of gynaecological cancer. We were disappointed that he couldn't provide a more precise timescale for this work, though acknowledge his indication that it would likely take 12 to 18 months. We are particularly concerned to read in the Minister's follow up letter of 2 October that much of the data that has been called for by clinicians and cancer charities is "still under consideration".

277. It is our view that the Welsh Government must work with health boards and the NHS Executive as a matter of urgency to provide as much transparency as possible. Publishing data on gynaecological cancer performance allows the public to understand how effectively the government is addressing this critical issue, and it is only by making this data available, that we can hold the Welsh Government to account for its policies and actions.

278. We also recognise the importance of clinical audits to provide a systematic way to review and assess the quality of cancer care and treatment. We are pleased to hear that Wales will have its own ovarian cancer clinical audit that will analyse data on patient outcomes and adherence to clinical guidelines, so that health boards can identify areas for improvement. We look forward to receiving a copy of this audit, once it is completed.

279. We would also like to thank Digital Health and Care Wales for agreeing to work with Dr Sadie Jones of the Wales Cancer Research Centre to analyse the data she has on the gynaecological cancers.

Recommendation 21. In its response to this report, the Welsh Government should set out what data on gynaecological cancer performance it intends to

[207] RoP [para 336], 27 April 2023

publish and by when. The publication of this cancer management data is essential for accountability, transparency, informed decision-making, and ultimately, improving the quality of cancer care and outcomes in Wales.

Recommendation 22. In its response to this report, the Welsh Government should set out what oversight it has of the cancer informatics system (CIS), and how it will ensure that the system is fit for purpose and will provide value for money. The response should include details of how the CIS is supporting a key objective in the Cancer Improvement Plan around the digitalisation of cancer pathways.

12. Gynaecological cancer research

Cancer research

280. Tenovus Cancer Care has described a "huge unmet need for gynaecological cancer research in Wales".[208] The first All-Wales Cancer Research Strategy was launched in July 2022.[209] The Wales Cancer Research Centre is responsible for implementing it.

281. We heard that the Wales Cancer Research Centre hasn't currently undertaken any specific work relating to the gynaecological cancers. Dr Sadie Jones, representing the Centre, told us:

> *"Cancer is a huge problem in many areas, and with limited resource you have to select where that funding goes, and, until recently, maybe other cancer sites have taken priority. But certainly from the Wales Cancer Research Centre perspective going forward, I've recently been appointed to one of their new steering committees, and there is acknowledgement that the situation for gynaecological cancers needs to change."*[210]

282. She added that (in her role as a clinician) she had tried to set up research in Wales to look at therapeutic vaccines for gynaecological cancers but her funding application was declined by Cancer Research UK (CRUK).[211] In response, Andy Glyde from CRUK said:

> *"We do fund some [research] that happens in Wales, but cancer research is a global thing.*[212]

283. CRUK said it spent three per cent of its budget on gynaecological cancer research in 2021-22, though that wasn't Wales-specific. Andy Glyde explained that Wales has to compete with other research environments for CRUK funding and said that unfortunately the medical research environment is not strong in Wales.[213]

[208] GC14 Tenovus Cancer Care
[209] Moving Forward: A Cancer Research Strategy for Wales
[210] RoP [para 137], 14 June 2023
[211] RoP [para 177], 14 June 2023
[212] RoP [para 140], 14 June 2023

Gaps in research

284. According to Fair Treatment for the Women of Wales, "women's health needs to be taken more seriously", not least in terms of research into health conditions and treatments which is inclusive of females.

285. Jo's Cervical Cancer Trust said there are gaps in knowledge about many areas of cervical cancer, including predictors or risk factors for persistent or recurrent HPV infections and cervical cell changes, and the cause of non-HPV cervical cancers.[214] While Target Ovarian Cancer talk of "a worrying decline in the UKs spend on ovarian cancer research" in recent years.[215]

286. Target Ovarian Cancer also highlighted that rarer sub-types of ovarian cancer have fewer treatment options:

> *"When considering how we can improve the treatment offered to everyone with cancer, we must ensure that rarer tumours along with other rare and less common gynaecological cancer types receive the focus and funding they need, so everyone has the best possible chance of survival."*[216]

287. Claire O'Shea, who has been diagnosed with Uterine Leiomyosarcoma, a rare and aggressive cancer, told us:

> *"Most charities and professionals working on sarcoma will tell you that research and breakthroughs on sarcoma are inadequate. It is a rare cancer, and even rarer when it appears in the reproductive organs. I have had to make life changing decisions based on research with 75 participants which hasn't been updated for years."*[217]

Funding for research

288. Dr Louise Hanna, representing the Wales Cancer Network's Gynaecological Cancer Site Group acknowledges that while further research is needed within gynaecological cancer, "there is growing academic interest and activity in Wales". She explains that Wales has representatives within research at national and

[214] GC10 Jo's Cervical Cancer Trust
[215] GC06 Target Ovarian Cancer
[216] GC06 Target Ovarian Cancer
[217] GC11 Claire O'Shea

international levels. However, she warns that "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".[218]

289. Dr Sadie Jones, representing the Wales Cancer Research Centre, told us that Wales could be a "good test bed" for cancer research but acknowledges that it may seem difficult to justify spending money on research when NHS services are under such immense pressure:

> *"However, when research is at the core of cancer service delivery, continual incremental improvement in patient outcomes will follow, helping to increase the flexibility and resilience of cancer pathways. This will ultimately serve to reduce waiting lists more quickly as well as offer patients the very latest treatments and interventions that research provides."*[219]

290. She added that unfortunately "research is frequently seen as an optional add-on, rather than an integral part of providing a high quality service for patients."[220]

291. According to Richard Peevor, representing the Royal College of Obstetricians and Gynaecologists (RCOG), "funding for research has been lacking over the last decade, and so we don't have a lot of in-house projects. We're relying on being part of English projects."[221] He noted that consultants working in gynaecological cancer have left Wales because they haven't been able to secure research funding.

292. Professor Iolo Doull, Chair of the All Wales Medicines Stratregy Group (AWMSG) told us that the infrastructure for clinical research isn't here in Wales, adding that "we spend less per capita" on health research than other parts of the UK.

Access to clinical trials

293. Clinical trials offer those diagnosed with cancer the opportunity to access new cancer drugs and treatment options. Target Ovarian Cancer say this is particularly important for those diagnosed with rarer tumours. Its recent

[218] GC15 Wales Cancer Network Gynaecological Cancer Site Group
[219] GC17 Wales Cancer Research Centre
[220] GC17 Wales Cancer Research Centre
[221] RoP [para 253], 27 April 2023

Pathfinder study[222] highlighted that there has been a 10 per cent decline in women being asked to take part in clinical trials between 2016 and 2022:

> *"This is despite there being a clear desire to take part in clinical trials with 61 per cent of women who took part in our study... saying they would have liked the opportunity to take part."*[223]

294. The British Islamic Medical Association (BIMA) highlighted that, for women from ethnic minority communities, they are even less likely than white women to take part in clinical trials.

295. Claire O'Shea told us that because she has a rare cancer, and there hasn't been enough research into this particular type of cancer, there are no effective treatments:

> *"... so my only option now, hopefully, is to get a clinical trial, and they are hard to come by. I'm working with a great oncologist at Velindre, and she was funded to start an immunotherapy trial, but she can't get the pharmaceutical companies to give her the drugs that she needs, because they can't see the eventual profit in a rare cancer. So, my only hope is that this immunotherapy trial happens, and it's being prevented."*[224]

296. Tenovus Cancer Care told us "we've got some real challenges in terms of being able to access clinical trials for the big drugs companies to come here to work with us, for us to get the numbers, to actually enable people to access those trials as well".[225]

297. The Deputy Chief Medical Officer told us there are 17 clinical trials for women with a gynaecological cancer in Wales. However, Dr Sadie Jones said there are currently six trials open in gynaecological cancer. She also said that "there is no funding for them from the health boards".[226]

[222] Target Ovarian Cancer, Pathfinder 2022: Faster, further and fairer
[223] GC06 Target Ovarian Cancer
[224] RoP [para 108], 10 May 2023
[225] RoP [para 106], 10 May 2023
[226] RoP [para 206], 14 June 2023

Our view

298. For women with rare gynaecological cancers, clinical trials can potentially be their only way of accessing treatment. Trials can offer innovative therapies that may not be available through standard treatments. For the patient, clinical trials may involve targeted therapies that can be more effective and potentially life-saving. Participation in clinical trials also contributes to the advancement of medical knowledge. Women who participate help researchers better understand the rare cancer, leading to improved treatment options in the future. That can be very empowering for women.

299. However, we heard that for some women, clinical trials can be hard to come by. Clinical trials are dependent on having experts in the field and we heard that the infrastructure to support clinicians with cancer research and clinical trials isn't necessarily there.

300. We must ensure that the decline in opportunities to take part in clinical trials is reversed, and that information about clinical trials is shared with women, especially women from minority ethnic communities, so they can make informed choices about whether to take part.

301. We also need to better understand why Wales is less competitive as a medical research environment than other parts of the UK.

Recommendation 23. The Welsh Government needs to take action, together with the Wales Cancer Research Centre, and with advice from the Wales Cancer Alliance, to develop Wales' medical research environment so that it can compete with other parts of the UK for research funding. This should include consideration of whether a centre of research excellence could be established specifically for gynaecological cancer research. We note this will require the political will and the redirection of some research funding.

Recommendation 24. In its response to this report, the Welsh Government should set out:

- how many clinical trials are currently open for women with a gynaecological cancer in Wales;
- how they will work with health boards to reverse the decline in clinical trials open for women with a gynaecological cancer; and
- how clinicians can be better remunerated for this work.

13. Palliative and end of life care

302. While our inquiry has largely focused on what can be done to improve prevention and treatment of gynaecological cancers, sadly we have seen first-hand through our video evidence that some gynaecological cancer diagnoses are terminal. Access to palliative and end of life care and support for women with a terminal diagnosis is therefore very important.

303. The Welsh Government published its quality statement for palliative and end of life care in 2022.[227] A national programme board has also been established to provide clinical leadership. Natasha Wynne from Marie Curie Cymru described the quality statement as "aspirational" but questioned whether there is enough capacity to turn it into reality.[228]

Increasing demand for palliative and end of life care

304. According to Marie Curie, research has previously forecast a drastic increase in demand for palliative and end of life care in the next two decades[229]. The Office for National Statistics estimate that by 2040, there will be an additional 5,000 deaths per year in Wales[230].

305. Dr Jo Hayes, Medical Director at Marie Curie, told us:

> *"We've got an ageing population, so more people are going to die, and the estimate is an extra 5,000 deaths a year in Wales. At the moment, probably about half of deaths in Wales are in hospital. That's not going to be able to continue, with the pressure on NHS services, and it's not the ideal place anyway for most people to die, in an acute hospital. So, more people are going to need and want to die at home, and nursing homes are the other area where there will be lots more deaths as we go forward to 2040."*[231]

306. She went on to explain that her clinical role is specialist palliative care in the community for the Vale of Glamorgan:

[227] Quality statement for palliative and end of life care, October 2022
[228] RoP [para 210], 29 June 2023
[229] GC02 Marie Curie
[230] Office for National Statistics
[231] RoP [para 137], 29 June 2023

> *"We [ ] look after patients who are dying, in partnership with GPs and district nurses, as a sort of triumvirate, if you like. There's lots of pressure on GP services, and so it's very difficult. There are shortages in district nursing, and difficulty with large caseloads in specialist palliative care as well. So, I would say we need much more resourcing to all of those roles to meet the needs of the population going forward in the next 10, 15 years. More people are going to need and want to die at home, and I'm not sure if we have quite planned enough for all of that."*[232]

Gender inequalities at end of life

307. According to the Cross-Party Group on Women's Health, research into women's experiences of end-of-life care is inadequate, and what there is suggests there are differences in how some women report symptoms, the pain they experience, and the treatment they receive as they approach end of life.[233]

308. The Women's Health Wales Coalition says Wales is part of a wider cultural landscape which has historically tended to marginalise women's health needs:

> *"There is a large body of evidence to suggest that women's reporting of symptoms can be over-looked or dismissed , something that can be hugely problematic when it comes to early diagnosis of a gynaecological cancer.*
>
> *This can lead to unmet palliative care needs, and ultimately, a poorer quality of life for women living with terminal illness, including a gynaecological cancer."*[234]

309. According to the Cross Party Group on Women's Health, there is evidence to suggest that women must report higher levels of pain (compared to men) for healthcare professionals to identify and document their symptoms:

[232] RoP [para 138], 29 June 2023
[233] GC07 Cross Party Group on Women's Health
[234] GC08 Women's Health Wales Coalition

> *"In some instances, women report feeling that their pain is wrongly attributed to a psychological rather than a physical cause."*[235]

310. Similarly, Marie Curie highlights evidence that shows women often report more severe daily feelings of pain, nausea, and fatigue, but may also have to report greater symptom distress than men for their pain to be acknowledged:

> *"Evidence suggests that this is partly a result of gender bias and women's pain sometimes being underestimated, with healthcare professionals being less likely to document symptoms. Research also discusses how women are more likely to have pain attributed to psychological rather than physical needs and to then be prescribed sedatives rather than the appropriate pain relief."*[236]

311. It also drew attention to biological differences when it comes to how females and males experience pain and respond to pain management, particularly opioids:

> *"Studies have demonstrated that there are disparities in how the male and female body receives and responds to the main pain relief drug prescribed at end of life – opiates. If women are prescribed opiates with no consideration of how their biology could be impacting the effects of the drug, their quality of life could be disproportionately affected."*[237]

312. Natasha Wynne, Marie Curie, told us:

> *"This isn't specific, necessarily, to gynaecological cancers, but again, anecdotally, just talking to bereaved relatives, sometimes opioids don't work for people, and they need to be believed if they're saying they're still in pain, even if they've had a high dose [...] So, yes, we just need to believe people and properly listen to them."*[238]

[235] GC07 Cross Party Group on Women's Health
[236] GC02 Marie Curie
[237] GC02 Marie Curie
[238] RoP [para 160], 29 June 2023

Early palliative care and end of life choices

313. Palliative and end of life care can be initiated at any point during a patient's journey and can include a range of holistic treatments focusing on psychological, social, and spiritual aspects of care. Palliative care is not the same as end of life care, and patients can be put on a palliative care pathway as soon as they're diagnosed with an incurable cancer.

314. Dr Jo Hayes told us:

> *"I think there's also a misconception, sometimes, that palliative care is just for the very end of life, whereas I'm sure you've all seen in the suspected cancer pathways, palliative care can come in quite early and help to manage people along the illness journey, if you like. We'd like to be able to provide a good and specialist service much earlier for some people."*[239]

315. Marie Curie raised concerns that some women may not be benefitting from early palliative care in the same way as men, and suggested that research into the reasons for this was needed.[240] It said that women are more likely to receive care and support from healthcare professionals and specialists rather than unpaid carers, because "many women express fears around feeling like a burden if they themselves need care from family and loved ones".[241]

316. It also said there are "massive inequities" in access to palliative care to do with ethnicity, age, rurality and deprivation:

> *"So, I indicated earlier that older people don't seem to have the same rates of access as people of, say, working age. Socioeconomic status as well: people from poorer areas don't necessarily have the same access. Rurality is another big issue, especially in Wales. We have a bit of a data issue, in that some of those characteristics aren't always collected. So, ethnicity is a key one there."*[242]

[239] RoP [para 157], 29 June 2023
[240] RoP [para 170], 29 June 2023
[241] GC02 Marie Curie
[242] RoP [para 185], 29 June 2023

317. Dr Jo Hayes told us:

> *"So, this is why, with the women and girls health plan at the moment, we think it's really important that palliative care is included in that, because we want a cradle-to-grave approach that really understands that quality of life doesn't stop just because you've got a terminal illness. We need to be thinking about it right until the end of life."*[243]

318. Marie Curie also make the point that women are less likely to want to die at home compared to men. This is assumed to be due to a greater understanding of the reality of caring for someone at home. It also highlights insufficient resources and capacity in health and social care community provision as a barrier to supporting women to die at home if this is their preference:

> *"The insufficient capacity in community provision could also be impacting on women's ability to die at home if this is their preference. Everyone in Wales should be able to die where they wish, if safe and feasible, and more research is needed to understand whether gender norms are currently inhibiting this."*[244]

319. We heard that 450 women die in Wales every year from a gynaecological cancer, but for women over 65 who die from these cancers, only three quarters of them are registered with specialist palliative care.

320. Dr Jo Hayes wants the Welsh Government to ensure:

> *"all women with gynaecological cancers who are likely to have complex symptoms or progressive disease that will shorten their life would be offered early access to palliative care, and that there's enough resource within palliative care to provide a good service to them."*[245]

Our view

321. It is important that people understand the difference between palliative and end of life care, because patients can be put on a palliative care pathway as soon

[243] RoP [para 134], 29 June 2023
[244] GC02 Marie Curie
[245] RoP [para 220], 29 June 2023

as they're diagnosed with an incurable cancer to help manage their pain as their illness progresses.

322. We agree with Marie Curie that the Welsh Government should ensure that all women with an incurable gynaecological cancer are offered early access to palliative care.

Recommendation 25. The Welsh Government should work with health boards and relevant stakeholders to ensure the benefits of palliative care are promoted to patients, general practitioners and clinicians in acute hospital settings to address the misconception that palliative care is only for the very end of life.

Recommendation 26. In its response to this report, the Welsh Government should provide an update on the progress it has made in implementing the quality statement for palliative and end of life care, and specifically how it is ensuring access to palliative care is underpinned by equity.