

# Gynaecological cancers

## Engagement findings

June 2023

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

### **Background**

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

### **Engagement**

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

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



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

## **The videos**

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

## **Thank you**

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

# 1. Summary of recommendations

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

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

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

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

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

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

**Claire**



**Linda**



## Judith



## 2. Key themes

### Awareness of symptoms

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

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

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

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

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

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

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

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

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

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## Lack of knowledge from medical professionals

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

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

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

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

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

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

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

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

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

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

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

### **Dismissed by medical professionals**

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

### **Delay of diagnosis**

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

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

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

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

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

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

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

### **Lack of communication**

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

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

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

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

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

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

## Patient and family care

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

### **Motivation to take part**

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

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

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

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

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