

Health and Social Care Committee,  
Senedd Cymru Bae Caerdydd,  
Caerdydd,  
CF99 1SN

12 April 2024

Dear Chair

Thank you for offering the opportunity to respond to the Welsh Government's response to the inquiry. I have been deeply disappointed by the tone and the lack of concrete commitments to any transformative change that can meet the challenges and needs of women in Wales now and in the future. The rhetoric that women's health in Wales is a priority doesn't appear to be met with the ambition and resources that it demands. Opening the response by saying that the vast majority of those receiving gynaecological cancer care report 'high levels of satisfaction' is not the measure by which Welsh Government or health boards should marking their own work. 1200 people are diagnosed a year, 470 people die, and only 34% of gynaecological cancers meet the suspected cancer pathway targets. Only 34%. Personally, I was first referred in February 2022 and didn't receive treatment for cancer until December 2022.

As a patient, at no point have I been asked about my satisfaction levels with the services I have received. So, I must question how systematic data collection is when it comes to patient satisfaction. As a 41-year-old woman who did everything 'right' including looking after my health, presenting early with symptoms, pursuing appointments when I was dismissed, obtaining my own medical records to review the standards of care I was given and demanding additional scans, I am still facing my own mortality as my cancer progressed to stage four under the care of my health board. My formal complaint was closed without satisfactory explanations of what might change as a result of my experiences.

I myself and many other women I have spoken to would not be reporting high levels of satisfaction, but are also deeply saddened to realise women are more likely to die in Wales as a result of gynaecological cancer. These standards, like the response to the recommendations, are not good enough. I am under palliative care now, and I am unlikely to survive to see an improvement in gynaecological cancer services, but I hope that by participating in work like this, my voice, along others, will be heard and action will be taken.

I have concerns related to the Welsh Government's response to all 23 recommendations, but I acknowledge that, as a patient, I do not have access to all the information I would need to scrutinise them fully. However, by drawing on my own experiences and those of the multiple women who contacted me as a result of giving evidence, I feel like I can provide some positive challenges.

1 & 2. While it is reassuring that these have been accepted and accepted in part; the plan has yet to be published, and therefore, we do not know if it meets the needs. The discovery report, published in November 2022, commits to a women's health network

within 6-12 months. As of April 2024, I am unable to find the members or the progress of the network. There is also a commitment to a women's health research prioritisation exercise due in April 2024. Again, I am unable to find ways to participate in this. The fact gynaecological cancers won't be addressed specifically is also a concern. We have no idea whether current measures will improve outcomes.

3. There are clear and urgent needs to improve outcomes for gynaecological cancers. The Welsh Government should prioritise this based on the abundant evidence. With no explicit commitment to research in this area, we can not move the dial for women.

4. Rejecting this commitment is surprising and disappointing. Given how far health boards are from meeting targets, and while pathways are being transformed, additional resources are needed to manage patients through the system. I am also unable to ascertain what the transformation looks like, so it is hard to feel confident that change can happen without a basic commitment to more resources.

5. If Welsh Government is to hold the NHS Executive to account, it should be able to tell us at what point the milestones are due to be published.

6. While I support the ambition and, indeed the assertion that everyone should have a keyworker, the experience for patients doesn't tally. I don't have one, due to long-term staff sickness. It is also imperative that patients can access their records digitally. Up until now, I have had to request paper copies that have taken up to 3 months to receive, and when I have received them, I have been able to spot errors in my care, like not being referred for a scan that another MDT had instructed. Patients need to be treated as partners, and this includes access to up-to-the-minute medical information.

7. This is a positive movement and should be welcomed. Further information on how they will operate and who can refer to them is essential. Under the care of my GP, I wouldn't have been referred as my symptoms were attributed to IBS.

8. The recommendation is to help the NHS reach 90% uptake. Stating the target is 90% isn't the same as outlining the support that will be offered to ensure the target is met. It would be welcome if the Welsh Government published current uptake levels.

9. As with many other responses, the financial implications are assessed to be within the current budget. If the services are currently resourced to the levels needed, would they not be closer to meeting their targets?

10. Encouraging to know that research is being undertaken.

11. If better information is to be given at the point of a smear test, would there not be financial implications for workforce training and provision of materials.

12. I can't recollect seeing a gynaecological cancer campaign in Wales, so I have no ability to scrutinise this statement. However, I did not know the symptoms of gynaecological cancer before I experienced it myself. A measure of campaign success is also information retention. If there have been previous campaigns, surveying women on their knowledge

would support an understanding of whether more needs to be done. There is little point in measuring outputs like campaign materials if outcomes and behaviours don't change.

13. I do not know what this looks like in practice or when it was implemented, but I personally didn't get a referral despite presenting with obvious symptoms of gynaecological cancer, and I know the same is true of several women who have contacted me as a result of giving evidence, or who are undergoing treatment at Velindre.

14. This system didn't work for me. The data should be better: how many times did women have to present to a GP before they got a referral? If 1200 women per year are diagnosed in Wales, and there is a conversion rate of 5%, this would indicate that 1.6% (24,000) of women in Wales on an annual basis are presenting and being referred with the symptoms of gynaecological cancer. If this is correct, it would indicate that further GP education and public awareness is needed for more clarity around the presentation of gynaecological cancer or further testing within the primary care setting, like blood tests etc. I accept that some women will have been diagnosed in emergency settings, so my figures are very ballpark. Knowing how many women are diagnosed in an emergency could potentially be a better indicator of how seriously GPs are taking symptoms and making referrals.

15. It is implausible to say women's health is a priority, knowing that only 34% of women meet the SCP targets, and not to commission urgent reviews into a cancer that has worse outcomes than the rest of the UK. The data collection is clearly hit-and-miss. This could be an opportunity for reform. I look forward to working with whoever picks up the mantle on this much-needed work.

16. Glad to see this recommendation accepted. Who are the experts across Wales, and does it include women and carers with lived experience?

17. This sounds positive. I have a rare cancer that ultimately is no longer categorised as gynaecological. I am now under the care of the sarcoma team, so I can't speak to this with my experience.

18. While my current team is amazing, I am finally being treated as an individual. My previous concerns have been dismissed and demeaned, and at times, my hospital care has been substandard, and my pain ignored, including an incident within the last week. Again, there is a gap between rhetoric and reality. The frequency of these incidents demonstrates to me that they are not isolated experiences.

19 & 20. Again, these sound positive, but with my limited knowledge, I have no way of scrutinising them.

21. This information should be accessible to people like me. Completing several pieces of evidence and work to inform the inquiry has been more than challenging, as has finding and interpreting data.

22. Without working knowledge of digital systems, all I can do is reinforce the need for patients to have easy access to patient information.

23 & 24. Without research knowledge, and with a rare cancer where I only have access to a couple of lines of treatment that are mostly ineffective, I can't overstate how important it is to address the research needs. In particular, pharmaceutical companies are reluctant to provide resources for research into rare cancers that ultimately won't be profitable. The lack of genomic profiling in Wales is also an enormous barrier to patients getting the most effective treatment possible.

25 & 26 - I am under palliative care, and I am close to several other women my age who are also dealing with stage 4 diagnosis; we are mainly in agreement that it doesn't meet our needs as younger women and the life and responsibilities that come with that.

In addition to the points above, I have a few more thoughts that have arisen as general comments on the response.

I have an additional plea to stop using the term 'vague symptoms' - we must move away from this language. I presented with symptoms of gynaecological cancer. The use of 'vague' is loaded with connotations and it breeds doubt. It is clear that often, the symptoms grouped together as 'vague' are simply symptoms of Gynaecological or other cancers. If we were to use language that reflected that, the symptoms might be treated with seriousness and urgency.

The report mentioned a large number of plans, reports, and networks that were difficult to cross-reference, and the distribution could easily dilute accountability. A clear commitment to gynaecological cancers should come in the form of a strategy that links all of the disparate work into one clearly navigable document.

It is also a concern that there are no clear resourcing or financial commitments. After every recommendation, it is indicated that there are no financial implications. If pathways are to be transformed, will they be cost-neutral, or do women deserve investment in a failing service?

I appreciate the work that the committee has undertaken so far to highlight the appalling experiences many women have had. I have no doubt the debate will be informative and well-informed. I look forward to seeing the progress of this work.

Kind regards,

A handwritten signature in black ink, appearing to read 'C O'Shea', written in a cursive style.

Claire O'Shea