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This response was submitted to the [Health and Social Care Committee](#) consultation on [Gynaecological Cancers](#)

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Ymateb gan: | Response from: Triniaeth deg i Ferched Cymru | Fair Treatment for the Women of Wales





FTWW Response to the Senedd Health and Social Care Committee's Inquiry into Gynaecological Cancers in Wales

13th January 2023

Name of organisation: Fair Treatment for the Women of Wales (FTWW)

Who we are: FTWW is the only patient- and service-user-led charity in Wales dedicated to addressing the health inequalities experienced by women¹ and people assigned female at birth. We support and empower those who are disabled and / or living with long-term health conditions, advocating for better health services and equitable access to them, particularly as many of the health issues which predominantly affect females have suffered historical lack of investment and prioritisation in Wales and beyond.

¹ Please note that references to women and women's health throughout this document should be considered inclusive of people observed & assigned female at birth, non-binary, trans-, and intersex people who have female reproductive organs and are at risk of a gynaecological cancer as a result.

This response includes:

- **An Overview**
- **Public Health and Prevention**
- **Training for Healthcare Professionals**
- **‘Women’s Health Hubs’**
- **Mental Health Support for those Affected by a Gynaecological Cancer**
- **Investment in Research**
- **In Conclusion**

Overview

FTWW would first like to congratulate the Committee on choosing to focus this inquiry on gynaecological cancers. As a women’s health equality charity, we would particularly like to see the Committee’s focus in this area reflect the fact that gynaecological cancers, like many other health conditions which solely or predominantly affect females, have suffered historically from a lack of prioritisation or investment, either in research or service provision. This is something we would like to see addressed during this Sixth Senedd.

According to the Royal College of Obstetricians and Gynaecologists (RCOG), in the UK each year over 21,000 women are diagnosed with one of the five gynaecological cancers (uterine or ‘womb’, ovarian, cervical, vulval and vaginal), and 7,700 women die. Symptoms vary between cancers but can include bloating, pelvic pain, bleeding between periods, pain during sex, itching and unusual vaginal discharge. Anyone with female reproductive organs can be at risk of gynaecological cancers, and so trans, non-binary or intersex people with a womb, cervix, ovaries, fallopian tubes, vagina, or vulva should also be aware of symptoms.

One major challenge in establishing what is working well and what isn’t with regards to pathways, services, and outcomes for patients with any of these five cancers is the tendency for providers to conflate them all under the umbrella term of ‘gynaecological cancer’, despite their having distinct risk factors, symptoms, and treatments. This needs to be rectified as soon as possible, with

data disaggregated, so that Wales is better equipped to identify and address gaps and barriers.

Whilst women make up some 51% of the population in the UK, traditionally, any consideration given to 'women's health' has focused mainly on maternity care, a comparatively small portion of women's lives. Whilst this remains of vital importance, there has been a lack of emphasis on gynaecological care / services and, even more so, other disease areas or issues which disproportionately and negatively impact females.

Health conditions which solely affect women and those assigned female at birth incur a significant cost burden to Wales: the ONS reports that women live fewer years in good health than men² and are more likely to be in poverty, requiring both social and financial support. These inequalities are likely to be compounded for those experiencing intersectional barriers, including people with legally protected characteristics and people who are neurodivergent.

Over recent times, evidence has emerged from across the UK showing that 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. Clinical studies have historically excluded females because of the perceived complications and expense associated with adjusting for hormone fluctuations. This has had a significant impact on the range and efficacy of medical treatments offered for a significant number of diseases, and the neglect of conditions predominantly affecting women, including gynaecological cancers.

The Cumberlege Report, 'First Do No Harm'³ is just one of several accounts which describe how women's self-reporting of both symptoms and associated healthcare-related experiences have been systematically dismissed or underplayed, leading to continued misdiagnoses and poorer outcomes. When it comes to pain, including both treatment of post-operative pain and in emergency settings, evidence suggests that women wait longer than men for pain relief⁴, and

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbynationaldeprivationdecileswales/2018to2020>

³ <https://immdsreview.org.uk/>

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https://gupea.ub.gu.se/bitstream/handle/2077/39196/gupea_2077_39196_1.pdf;jsessionid=BF63D6E79F2A419762DC8B63FF010F91?sequence=1

are more likely to be given sedatives instead⁵. At the same time, data reveals a longer time from the onset of symptoms to diagnosis in female patients in 6 out of 11 types of cancer⁶ with women having to visit their GP more often than men to get a diagnosis. FTWW's members frequently report 'normalisation' of symptoms as a reason for further delay, whether that is due to inaccurate information they have encountered throughout their lives or lack of confidence in clinical settings, or lack of awareness on the part of a healthcare professional. Further, some report having symptoms erroneously attributed to a psychological cause. The net impact of this is significant diagnostic delay, worsening prognoses, and considerable impact on wellbeing. Evidence suggests that this extends to the various symptoms of the five gynaecological cancers, which can have catastrophic consequences for those affected.

The pandemic has further exacerbated delays in diagnoses and treatments for those affected by a gynaecological disorder – some of whom will likely have a form of gynaecological cancer. As a proportion of the population, gynaecology services have been worse hit by pandemic-related cancellations and reprioritisation of care than any other specialty. As a result, countless women are on unacceptably long waiting lists, some of whom will wait years for treatment. The RCOG's report, 'Left For Too Long'⁷ suggests that this is a direct result of the specialty being 'overlooked' in terms of patients' quality of life, staffing, and theatre time.

It is also worth pointing out that improving women's health is not only essential from the individual's perspective but also from that of wider society: women are more likely than men to be primary caregivers for younger and older generations⁸ whilst also making up almost 50% of the UK workforce, with rates of women in full-time employment rising faster than that of men⁹. Given these significant responsibilities, women's health is fundamental to the well-being of Wales as a nation and it is in this context that we are pleased to see the Welsh Government commit to co-producing with patients and public a plan for the health of women

⁵ <https://link.springer.com/article/10.1007/BF00289259>

⁶ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0127717>

⁷ <https://www.rcog.org.uk/about-us/campaigning-and-opinions/left-for-too-long-understanding-the-scale-and-impact-of-gynaecology-waiting-lists/>

⁸ <https://www.carersuk.org/policy-and-research/key-facts-and-figures/>

⁹ <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes>

and girls, starting with its Quality Statement, published in July 2022¹⁰. Undoubtedly, any future plan should include gynaecological cancers – research, information, awareness, prevention, treatment, and care.

A Wales-wide Women’s Health Plan for Wales would go a long way to addressing both wider inequalities and regional variations in service provision reported by patients in different health boards and across national borders. Where they exist, NICE or equivalent clinical guidelines are not always followed in Wales, despite their constituting evidence of best practice. The result is inconsistencies in services and inequality of outcomes for patients. FTWW is aware of incidences where medicines and / or treatments have not been made available to patients in Wales in the same way as they are to patients in England, and this includes for gynaecological cancers. We would ask that the Committee revisit Mark Drakeford (then Health Minister)’s assertion that the border between Wales and England would not see Wales patients less able to access medicines, treatments, services, or clinical trials than their counterparts elsewhere in the UK.

A Women’s Health Plan for Wales should be applicable across all health boards and ensure high quality, evidence-based, multi-disciplinary pathways are established for patients, enabling uniform and easy access to appropriate services wherever they may be located, whether this be in a specific health board or across the border in England. Historically, the lack of awareness and investment in women’s health conditions, including the individual gynaecological cancers, has seen a correlating lack of research and innovation so a Women’s Health Plan for Wales should focus on addressing these issues as well as ensuring the development of regional collaboration and joined-up care, clearly and consistently signposted for patients and their local healthcare providers, whether that be the GP, nurse practitioner, or secondary and tertiary care consultants.

As the Committee has noted, the poor outcomes experienced by those affected by gynaecological cancers in Wales is alarming – but also powerfully evidences the need to tackle wider health inequalities in Wales. As per the ONS, not only are women generally experiencing more years with activity-limiting illness and decreasing life expectancy, but those also who live in more deprived circumstances and areas can expect to see an even more negative impact on their

¹⁰ <https://www.gov.wales/quality-statement-women-and-girls-health-html>

lives and wellbeing¹¹. Evidence suggests that black and minority ethnic women, disabled women, and older women are more likely to be amongst those who experience these intersectional inequalities and the consequences of them on their health. Meaningful progress in addressing inequalities of this nature will require a consistent and joined-up approach across all sectors, with dedicated Welsh Government leadership and long-term investment required to tackle the root causes.

The Welsh Government needs to facilitate an operating environment that includes citizens, communities, public bodies, not-for-profit and third sector, and the private sector as equal partners. Priorities should include giving people a greater voice in defining solutions and making partnerships fit for purpose, as per the Welsh Government's commitment to co-production at every level, activity that we would urge the Committee to scrutinise.

In light of the above, we would call upon the Committee to consider:

- **The co-production and implementation of a Women and Girls' Health Plan which should include actions to address underlying and multi-generational health inequalities and disparities affecting females and see practical steps taken to improve medical research, efficacy of treatment, and service provision across the country, not least for gynaecological cancers.**
- **That the Welsh Government and NHS in Wales adopt a life-course approach to women's health which, in line with Prudent Healthcare Principles, includes regular health checks and data collection / analysis to identify individual patients' concerns, speed-up diagnoses and access to appropriate interventions, and pre-empt health issues that may arise later in life, including some of the gynaecological cancers.**
- **That patients in Wales are able to access optimum treatment and consistent high-quality service provision, including specialist tertiary care, no matter where in Wales they live. This should include consideration of**

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbynationaldeprivationdecileswales/2018to2020>

the remit and make-up of the Welsh Health Specialised Services Committee so that women's health and gynaecology, including gynaecological cancers, are prioritised and that there is patient involvement in decision-making.

- **An independent inquiry into the Individual Patient Funding Request process which doesn't always appear to be effective in enabling patients to access new medicines and treatments for gynaecological cancers.**
- **That there is support and investment in co-produced research into the impact of women's health conditions on patients and the wider population, investment in clinical trials, and disaggregation of emerging data by sex and gender, and that patients in Wales are able to take advantage of research findings and clinical trials / developments.**
- **That there is investment in enhanced training for healthcare professionals in Wales, including equality, diversity & inclusion training, social model of disability training, identifying & addressing unconscious bias training, and advanced clinical skills training as required.**
- **That there is developed a public health approach which focuses on education / awareness and prevention and early intervention in women's health, which would include awareness of risk factors and symptoms linked to the different gynaecological cancers.**
- **That there is embedded in Welsh Government a sustainable approach to resourcing specialist third sector organisations, enabling a fully co-productive approach to women's health strategy and service design in Wales.**

Public Health and Prevention

FTWW's 2021 manifesto¹² highlights the important role public health awareness campaigns and literature can play in ensuring early intervention in women's health-related issues, preventing harm, and reducing long-term costs to services. This also applies to gynaecological cancer.

¹² <https://www.ftww.org.uk/2021/wp-content/uploads/2020/11/FTWW-Manifesto-English-FINAL.pdf>

Public Health Wales already plays a key role in the delivery of screening for breast and cervical cancers. However, of equal importance is PHW's role in messaging, awareness, and education, all of which should feature in an effective, long-term endeavour to improve outcomes for those affected by a gynaecological cancer. Public Health Wales's stated aim of 'supporting the development of a sustainable health and care system focused on prevention and early intervention'¹³ should include raising the public profile of menstrual health and associated symptom awareness, including those potentially linked to a gynaecological cancer, so that women are better equipped to identify issues and seek both medical help and linked support.

As already touched-upon, the reasons for delayed help-seeking and diagnoses are complex but, in part, they can be attributed to societal myths and taboos which normalise symptoms associated with periods, such as pelvic pain and heavy bleeding, whilst also preventing open, accurate discussion about these issues and others, like bowel movements. The result is additional challenges in learning what is normal and what isn't, and a lack of either knowledge or confidence to pursue medical assistance and a diagnosis.

Clearly, therefore, there is a role for schools and colleges to deliver age-appropriate menstrual wellbeing education, something that would have both an immediate and long-term benefit: immediate because young people will have the information they need to challenge misconceptions and ask for help; long-term because our future generations of employers, medical professionals, and healthcare workers are in today's classrooms. Teaching menstrual wellbeing now sees women's health – including gynaecological cancers - properly understood, supported, and treated tomorrow.

It is of equal importance that public health messaging on the signs and symptoms of menstrual and gynaecological disorders, including cancers, extends beyond schools and colleges. NHS Wales-endorsed literature in a wide range of settings, including and beyond healthcare, would be advantageous and this should be made available in a range of accessible formats. However, given the context of existing taboos around gynaecological symptoms and the impact this is having on patient prognosis, we would also like to see a co-produced mainstream and multi-

¹³ <https://phw.nhs.wales/about-us/our-priorities/>

media campaign in Wales, one that extends into NHS workforce training and healthcare improvement, so that patients can start to see the benefits of increased awareness in their clinical appointments – this is important because, according to the Eve Appeal, unlike breast cancer, there has been no improvement in patient outcomes for gynaecological cancers over the last 30 years.

The numbers affected by gynaecological disorders, including cancer, make this area a significant cost-burden to the Wales economy and a major factor in decreased wellbeing for females, their families, and communities; as such, we would urge the Committee to ensure that:

- **Educational establishments throughout Wales are properly resourced to provide consistent, high-quality materials and teaching on the topic, thereby avoiding variation and further inequality**
- **Voluntary sector organisations are adequately funded to deliver teacher training and create materials which complement teacher-led lessons**
- **Menstrual Wellbeing Education be formally timetabled within schools' curricula**
- **Public Health Wales makes women's health, menstrual wellbeing, and associated health conditions, including gynaecological cancers, a key part of their future planning in line with the prevention and early intervention agenda, so that women have easy access to relevant literature and are sufficiently informed and empowered to seek help**
- **Women's health planning in Wales maps and learns from examples of good practice which see multiple opportunities for women to discuss with healthcare professionals their gynaecological health, symptoms, and next steps**
- **The Committee and other public service bodies within Wales work with organisations like FTWW to ensure co-production of strategy and resources, including a long-term media campaign to raise awareness.**

Training for Healthcare Professionals

FTWW members, and women more generally, have long argued for improvements in the healthcare they receive, not least an increased awareness on the part of healthcare professionals of menstrual and gynaecological health conditions. This is particularly pressing when it comes to making a prompt diagnosis of a gynaecological cancer, where treatment needs to be commenced as early as possible to improve patient prognosis. Evidence suggests that one of the most problematic barriers to prompt diagnosis is the ‘normalisation’ of symptoms on the part of public and professionals, resulting in their being under-reported, dismissed, or wrongly attributed to a different cause. Whilst there remains no quick and easy diagnostic tool for use in primary care, this can lead to unacceptable delays in making a referral for appropriate investigations and treatment. Some patients have reported finding themselves in gastroenterology or colorectal appointments for what turns out to be a gynaecological issue, so it is important that these specialties are also clear about next steps if a patient presents with signs indicative of gynaecological cancer.

Whilst it is clear that diagnostic tools need to be developed and made universally available as soon as possible, in the meantime, increased vigilance on the part of all relevant medical professionals is essential. One key element of this is enhanced training, both initially and as part of continuing professional development. It would be useful to know how far gynaecological symptoms and conditions – including cancers – are covered in medical schools and to establish whether there is scope for that to be improved. It would also be useful for information about gynaecological cancers to be disaggregated: at present, all five forms of gynaecological cancer will tend to be considered under the one umbrella term which isn’t necessarily helpful, as they have quite distinct risk factors and symptoms.

Of equal importance is a change in culture which too often sees women reporting feeling unheard and disempowered. Policy and legislation in Wales focus upon the benefits of ‘shared decision-making’ and service-users having ‘voice and control’, yet women regularly report feeling that they’re at the mercy of biases which under-estimate the seriousness of their symptoms and knowledge of their own bodies. This can, in part, be attributed to insufficient research and training

on health conditions predominantly affecting women, but historical gender stereotyping and a wider, societal tendency to either underplay or silence discussion of gynaecological symptoms also play a key role in making medical appointments often unsatisfactory, even traumatic, for women.

FTWW has heard reports from patients undergoing gynaecological outpatient procedures, including hysteroscopy (a tool used to help make a diagnosis of uterine cancer), where they have not been provided with sufficient information in advance to make an informed choice about the process and have experienced severe pain as a result. Very sadly, some of these women are traumatised to the extent that they are reluctant to engage with health services subsequently, which could be catastrophic for those who need urgent investigations and treatment in the future. We are concerned that, as the NHS in Wales increasingly moves towards outpatient service provision to reduce pressure on inpatient beds, a growing number of women will undergo similarly negative experiences - it is therefore of the utmost urgency that guidance of best practice on hysteroscopy and other outpatient gynaecology procedures is co-produced, implemented, and properly monitored, with patient experiences recorded and acted-upon to improve the service on offer.

To both reduce diagnostic delay associated with gynaecological cancers and improve women's experiences in clinical settings, the Committee should consider:

- **How far 'women's health', including menstrual and gynaecological conditions and cancers are covered in education for healthcare professionals in Wales and whether there is scope for further improvement and co-production of additional training.**
- **Recommending that medical training and continuing professional development includes co-produced modules relating to identifying & challenging unconscious bias, equality & diversity, and the social model of disability**
- **Recommending investment in advanced skills nurses specialising in women's menstrual, reproductive, sexual, and gynaecological health,**

ensuring provision across Wales and in every health board, within primary care and / or Women's Health Hubs

- **Recommending investment in the continuing professional development and advanced skills training of gynaecologists and associated professionals in Wales so that outpatient and inpatient services continue to improve**
- **Calling for an audit of outpatient hysteroscopy services in every health board in Wales, using a co-produced proforma which can accurately capture patients' experiences and inform future service delivery**
- **Recommending continuing professional development for gastroenterologists and colorectal doctors in Wales so that they are equipped to identify and act upon symptoms which might indicate a gynaecological cancer, in light of the fact that symptoms can present in such a way as to see patients accessing their services.**
- **Ensuring that development of screening and diagnostic tools for the 5 gynaecological cancers is prioritised in Wales.**

'Women's Health Hubs'

One possible way forward for improving women's gynaecological health is to provide what are commonly being described as 'Women's Health Hubs', as outlined in the Royal College of Obstetricians and Gynaecologists, 'Better for Women' report¹⁴, and which are now a focus for those developing and implementing England's Women's Health Strategy.

Such 'hubs', whether physically situated in a community building or by way of personnel linked up in a virtual network should offer a one-stop-shop for routine gynaecology, including the facilitation of pelvic examinations and ultrasound scanning, sexual health, contraception, screening, and associated services such as pelvic pain management, physiotherapy, low-level mental health care, and drop-in Menopause Café-style self-management and support. Staffed by personnel with specialist training in menstrual, sexual, reproductive, and gynaecological health – including advanced nurse practitioners - they should also enable

¹⁴ <https://www.rcog.org.uk/better-for-women/>

straightforward access to more specialised testing, procedures, and interventions where necessary which should improve early detection, treatment, and outcomes for patients with a gynaecological cancer. Hubs or Networks of this nature should exist in and across every health board, enabling regional collaboration where required, and be accessible to all. Technological advances should enable alternative ways of engaging with service-users depending on patient choice and need.

We are aware of concerns that ‘separating’ aspects of women’s health in this way might lead to de-skilling of some of the healthcare workforce and, potentially, poorer experiences for patients as a result. However, we believe that this need not be the case and that there should also be a role for ‘Women’s Health Hub’ practitioners in providing outreach and additional training to other members of the NHS workforce so that there is a seamless offer to patients. Indeed, central to the success of Wales’s ‘Women’s Health Hubs’ would be a holistic, multi-disciplinary approach and efficient, informed communication between the various teams both within and beyond it. The patient would be able to take advantage of joined-up management of complex care needs, access to a range of support and accompanying (electronic) notes, and, potentially, a self-referral mechanism which empowers women and enables them to be proactive in the management of their health and healthcare needs.

We would ask that the Committee:

- **Liaise with those developing the NHS Wales Women’s Health Plan to explore the feasibility of ‘Women’s Health Hubs’ or their equivalent as part of its work**
- **Call on Welsh Government and NHS Wales colleagues to link up with those leading on the development of Women’s Health Strategy and ‘Hubs’ in England (Professor Dame Lesley Regan) to share learning and establish facilitators and barriers to setting up similar mechanisms in Wales.**

Mental Health Support for those Affected by a Gynaecological Cancer

FTWW's members have long pointed out the difficulty in accessing appropriate mental healthcare from the NHS in a timely and seamless fashion – but this has become even more challenging as a result of escalating demand incurred by the pandemic. Now, more than ever, mental health strategy needs to be co-produced with patients, their advocates, and the third sector so that investment can be targeted, and services delivered, which meet patients' needs at the right time and place. This would include mental health support offered to those who are diagnosed with cancer or are living with chronic pain, for example, as the impact of these physical health issues on psychological wellbeing can be considerable.

As an organisation representing those living with chronic and recurrent illness across Wales, we are very much aware of the need for equitable provision of lower-level therapies and psychological interventions for those living with physical health problems and associated trauma. This would include during and after a gynaecological cancer diagnosis and be offered as part of a multi-disciplinary package of care supporting a holistic approach to symptom management. As it stands, there is a real disconnect between mental and physical health, with some professionals not appreciating how both physical symptoms of disease (i.e., pain) and a delayed diagnosis, where those symptoms may have been repeatedly missed, can contribute to escalating anxiety, depression, and trauma – this aside from anxiety and depression typically experienced by patients with a cancer diagnosis. It is vital this is addressed, by ensuring a joined-up approach to services, with the person (patient) at the centre.

Experiencing stressful, frightening, or distressing events – such as being diagnosed with a gynaecological cancer - can have a long-term impact on someone's mental health and wellbeing. Even when a patient is in remission from the disease, the stress of the experience can lead to the development of conditions like post-traumatic stress disorder (PTSD) and complex post-traumatic stress disorder (complex PTSD). Complex PTSD can occur when someone has experienced multiple and persistent traumas, intersectional inequalities, and oppression, such as ableism, racism, and gender-based violence. As a charity supporting disabled women, FTWW is very much aware of the various stressors experienced by our community, including medical and / or health trauma. Current service provision is

often not designed with women's specific needs and vulnerabilities in mind, which can further exacerbate mental health difficulties. Certainly, where mental health support for those with cancer and / or any other co-morbidities are concerned, it seems that there the third sector will often be responsible for delivering services – but these aren't necessarily clinical bodies with medical staff. For patients with more complex clinical needs, the NHS should be suitably equipped to provide care, whilst for lower-level support, the third sector should be offered sustainable funding so that they can continue to provide services.

Neurodivergent women, including those who are autistic and or living with attention deficit hyperactivity disorder (ADHD), often encounter additional barriers to healthcare. The delayed diagnosis and support they typically experience with regards to these issues can lead to poorer health outcomes more generally, often because they haven't found clinical spaces accessible or, indeed, 'friendly' to them and their needs. There is a great deal of evidence to suggest that for those with a pre-existing diagnosis of a mental health condition or neurodivergence, it can lead to assumptions that their physical symptoms are attributable to that, making effective dialogue and shared decision-making difficult to achieve. The inherent danger in this is that those patients affected become reluctant to engage with services at all, resulting in poorer prognoses and increased risk to health.

As well as experiencing prejudices and barriers based on 'formal' diagnoses of mental health conditions or neurodivergence, FTWW members often recall incidences where physical symptoms and conditions have been erroneously attributed to a non-existent mental health issue. Many attribute this situation to historical prejudices and stereotypes, where women's symptom reporting is underplayed or dismissed as being a result of the 'female psyche' and a tendency to be more depressed, anxious, and 'hysterical'. Where gynaecological cancers are concerned, it is of vital importance that these issues are addressed if we are to improve patients' prognoses. Healthcare providers should be offered a range of co-produced and co-delivered training on a wide range of related topics such as identifying and challenging unconscious bias, the social model of disability, equality, and inclusion, if we are to see improved access and outcomes for disabled and otherwise marginalised patients.

FTWW's research suggests that there continues to be a lack of capacity to record data on either patient need, or patient-reported experiences and outcomes, which then leads to a lack of appropriate services or pathways. These discussions – and associated actions – should form part of a co-produced mental health service, equipped to cope with the needs of those with a gynaecological cancer diagnosis and other long-term health conditions.

We would ask the Committee to consider:

- **Ensuring future mental health strategy and services in Wales are co-produced with patients, their advocates, and the third sector so that investment can be targeted, and services delivered, which meet patients' needs at the right time and place, including for those with a gynaecological cancer diagnosis**
- **Ensure that the Welsh Government and NHS Wales make patient-reported experiences and outcomes a key part of data collection and analysis in Wales, enabling the development of appropriate services or pathways.**
- **That for patients with more complex mental health needs associated with a cancer diagnosis, the NHS is suitably equipped to provide care, and that the third sector is sustainably resourced to provide lower-level psychological support.**
- **Ascertaining how far healthcare providers in Wales are undertaking training on topics such as identifying and challenging unconscious bias, the social model of disability, equality and inclusion, so as to improve access and outcomes for disabled and otherwise marginalised patients.**

Investment in Research

More research into women's health, including conditions which predominantly affect them, is a matter of urgency and something in which Wales should play a leading role. Gynaecological cancers are a clear example of where investment in both clinical and sociological research is required. This must include the development of better diagnostic tools and improved treatments and, also,

analysis of women's experiences in healthcare settings more generally so that diverse needs can be better understood, and an evidence-base created from which service delivery can be derived.

FTWW is aware of Welsh Government commitments to developing a 'Women's Health Research Fund' and would be keen to know more about progress being made in this regard, including any stipulations on research areas and topics. We would particularly welcome assurances that any research fund of this nature will involve women, patients, service-users, and the third sector in decision-making and prioritisation of topics, as well as a requirement that any research undertaken is co-produced with women themselves.

The Committee should consider:

- **Ensuring that research into the diagnosis and treatment of each of the five gynaecological cancers is prioritised in Wales, and that the country is in a position to facilitate associated clinical trials and implement results**
- **Calling for investment in co-produced research into patients' experiences of living with and managing gynaecological cancers in Wales and oversee implementation of recommendations**
- **Calling for investment in co-produced research to investigate patients' experiences of gender bias in healthcare provision and services in Wales and oversee implementation of recommendations**
- **Scrutinising progress on developing a Women's Health Research Fund in Wales.**

In Conclusion

Fair Treatment for the Women of Wales (FTWW) would be pleased to assist members of the Senedd Health and Social Care Committee with any further work on this Inquiry and related work.

Thank you.