

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Canserau gynaeolegol](#)

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

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Ymateb gan: | Response from: Clymblaid Iechyd Menywod Cymru | Women's Health Wales Coalition





Response to the Senedd Health and Social Care Committee's Inquiry into Gynaecological Cancers in Wales, January 2023

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This response will discuss:

- Overview
- Cancer workforce
- Barriers to securing a diagnosis and early treatment of a gynaecological cancer
- The importance of accessible, accurate, widely available information
- Increasing uptake of cervical screening
- Faster diagnosis of ovarian cancer
- Diagnosing Uterine (Womb) Cancer
- End of life care for women and people with a gynaecological cancer diagnosis
- Research and data
- Priority given to planning for new innovations
- Concluding remarks

Overview

We are pleased to provide a response to this inquiry on behalf of the Women's Health Wales Coalition, a group of around 80 third sector organisations, clinicians, academics, and patient advocates who have come together to support the Welsh Government and NHS in Wales to develop a plan to improve the health and wellbeing of women, girls, and people assigned female at birth in Wales¹. The Coalition believes that this Plan should include gynaecological cancers and other diseases (disproportionately) affecting women; as such, we are pleased to support the Senedd Health and Social Care Committee's prioritisation of this issue.

It is vital that underlying and multi-generational health inequalities and disparities affecting women are considered as part of this inquiry, with steps taken to address negative and dismissive attitudes like those described in 2020's Cumberlege review, 'First Do No Harm'², and practical measures implemented to improve medical research, efficacy of treatment, and service provision across the country.

Women, girls, and those assigned female at birth (AFAB) make up 51% of the population in Wales. Despite this, medicine and healthcare services have not necessarily met their needs. Inequalities can be seen across Wales in the provision of women's health services, but they also exist in the care of diseases which impact both men and women, including cancer generally, with women experiencing comparatively poor outcomes. Ovarian cancer has around a 47% survival rate at 5 years, compared to 95% for testicular cancer, whilst data from the Office of National Statistics (ONS) reveals that women with bladder cancer have a much lower survival (62% average for 2012 to 2014) than men (75% average for 2012 to 2014). Whilst bladder cancer is not gynaecological disease, the explanations given for the difference in survival rates are interesting in that they reflect findings associated with both gynaecological cancers and other conditions which affect both men and women. The ONS reports that, 'Women with bladder cancer...tend to be diagnosed at a later stage which contributes to

¹ Whilst the Coalition's response to this inquiry will generally refer to women, we would ask that this be considered inclusive of girls, people who have been assigned female at birth including non-binary and trans gender individuals, and intersex people.

² https://www.immndsreview.org.uk/downloads/IMMDSReview_Web.pdf

the overall differences in survival. Longer waits for diagnosis and higher proportions of emergency diagnoses in women with bladder cancer may also contribute³.

Further ONS data reveals that women can expect to live fewer years 'disability free' than men⁴ so it is clear that inequalities are costing women their health, their wellbeing and, sometimes, their lives.

The Welsh Government's long-term plan for health and social care, 'A Healthier Wales'⁵ makes clear its aim of ensuring person-centred care across the country. However, it fails to account for substantive preexisting inequalities which prevent person-centred care being a reality for many groups in Wales, not least women. For this reason alone, it is important that decisive action is taken to consider and address intersectional inequalities which perpetuate poor health outcomes for women, including the historical lack of investment and research into health conditions which disproportionately affect women and people AFAB, not least gynaecological cancers, and the subsequent lack of awareness, diagnosis, specialist treatment, and support for those affected.

Wales is not an exception in this regard but 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 dismissed⁶, something that can be hugely problematic when it comes to early diagnosis of a gynaecological cancer.

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

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalbystageatdiagnosisforenglandexperimentalstatistics/adultsdiagnosed20122013and2014andfollowedupto2015>

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbynationaldeprivationdecileswales/2017to2019>

⁵ <https://www.gov.wales/sites/default/files/publications/2019-10/a-healthier-wales-action-plan.pdf>

⁶ Cleghorn, Elinor 'Unwell Women: Misdiagnosis and Myth in a Man-Made World', Dutton, June 2021

relief⁷, and are more likely to be given sedatives instead⁸. 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 cancer⁹, with women having to visit their GP more often than men to get a diagnosis¹⁰. Further, many women report having their symptoms dismissed as either 'normal' or erroneously attributed to psychological causes¹¹, resulting in significant diagnostic delay, worsening prognoses, and considerable impact on wellbeing¹².

Coalition members provided considerable evidence from the groups they represent who feel like their concerns are not taken seriously by their GP or are told to wait to see if their symptoms abate. Patients reported increased concern, anxiety, frustration, and anger as a result.

Jo's Cervical Cancer Trust, one of the Coalition's member organisations, provided the following account from a Wales patient: 'My health care team for my treatment were generally very good. My experience of the nurse who took my cervical screening was not, alongside the communication from admin staff who said, "well no news is good news", when I was waiting for results. Also, one nurse on the ward was not compassionate at all towards me and hurt me when giving me my injection for blood thinning. I don't blame her as an individual though, I guessed that she was overworked, under paid and probably hadn't stopped for food! Care needs to be at all levels of the system for others to be able to be compassionate in their jobs too'.

Of course, all the above assumes that women feel sufficiently confident to seek medical help in the first instance: entrenched taboos around gynaecological organs and symptoms can make it more challenging for women to speak openly about issues concerning them, or even fully appreciate themselves what is

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

⁸ <https://link.springer.com/article/10.1007/BF00289259>

⁹ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0127717>

¹⁰ <https://bmjopen.bmj.com/content/3/6/e002861>

¹¹ <https://europepmc.org/article/med/9004374>

¹² <https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562>

‘normal’ and what requires medical attention. This can be further complicated by intersectional barriers such as race, disability, and gender identity.

According to another Coalition member organisation, 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 (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.

Prevention and early intervention are at the centre of a life-course approach to women’s health. For cancer care, this means equitable access to cervical screening and HPV vaccination, efficient diagnosis and treatment pathways, and better symptom awareness of all gynaecological cancers.

Providing women with high-quality care for gynaecological cancers requires an adequately staffed, motivated, well-trained, and well-supported workforce, and so underpinning all recommendations is the need to address existing cancer workforce challenges.

Cancer workforce

Current numbers of gynaecological cancer specialists and multidisciplinary team members, including specialist cancer nurses, are well below what is needed to deliver an optimal service. It is imperative that the Welsh Government puts in place fully funded, long-term plans for the NHS Wales workforce to address staffing issues and that it ensures regional collaboration, across health board boundaries and into England, takes place to improve patient outcomes and experiences.

The RCOG points out that, in the UK, there has been a concerning decrease in the number of trainees completing subspecialist training (SST) in Gynaecology Oncology (GO), with a recent RCOG O&G workforce report finding a 32 percent decrease in GO SST over the last five years and an uneven geographical

distribution of subspecialty consultant jobs and SST posts compared to regional demographic requirements. This is particularly concerning considering the ageing population in Wales, which is expected to lead to increased demands on gynaecology services within the next 15 years. The Welsh Government's own 2021 statistics reveal that there were more people than ever before in older age groups in Wales. The proportion of the population who were aged 65 years or older was 21.3% (up from 18.4% in 2011), with a larger percentage of the population aged 65 years or older than all English regions except South-West England¹³.

It is imperative that the NHS in Wales is able to keep pace with projected patient and clinical need and ensure that sub-specialist consultant appointments and training posts are more evenly distributed based on the demography of each health board. Investment in sub-specialty training centres, which can be utilised by clinicians across Wales, would be one way of addressing regional disparities in professional development.

In addition, there is an urgent need for more specialist cancer nurses, who can provide clinical and emotional support and personalised information for people with cancer. As the RCOG reports, specialist nurses have the potential to reduce treatment costs, increase efficiency, drive innovation, and provide valuable information for service re-design, playing a hugely important role in multidisciplinary care. Macmillan Cancer Support recommends that Governments across the UK invest a total of around £170 million in funding the training costs of nearly 4,000 additional cancer nurses by 2030.

Jo's Cervical Cancer Trust highlights how workforce pressures in colposcopy have been documented for several years with the Wales Cancer Alliance reporting in 2019 that, 'the colposcopy workforce is aging, with vacancies in many health boards'. In a workforce that is already under pressure, significant numbers entering retirement will have a tangible impact on patient care. According to Jo's Cervical Cancer Trust research, capacity and workforce pressures are also felt by women attending the service, with 42% of survey respondents saying that they didn't have enough time to consider their options or make decisions and 29% saying they hadn't had enough information and support to understand the

¹³ <https://www.gov.wales/population-and-household-estimates-wales-census-2021-html>

benefits and risks of treatment. A poor patient experience could lead to reduced inclination to attend again.

Finally, given the Welsh Government's commitment to person-centred care, it is important that patients with the multiple health needs that come with a cancer diagnosis are able to access support to navigate complex healthcare pathways, in the form of co-ordinators, navigators, and / or administrators, people who are equipped to liaise with patients and ensure clinics operate efficiently. Such personnel should receive full training for their roles and work over a realistic number of services.

Barriers to securing a diagnosis and early treatment of a gynaecological cancer

The pandemic has reflected and amplified long-standing intersectional inequities in healthcare. Intersectionality (a term coined by Kimberle Crenshaw in 1999) illustrates that people's identities and circumstances can overlap and essentially accumulate, further compounding their experiences of discrimination. The Women's Health Wales Coalition is particularly concerned about how these intersectional inequalities can impact on people's experiences and outcomes when it comes to their health and wellbeing and would urge the Welsh Government to undertake work to unpick and actively address them.

Black and ethnic minority women are one group particularly at risk of experiencing disproportionate health inequality in the UK, with numerous reports detailing their not being listened-to, believed, or respected in healthcare settings. Black women have told us that bias permeates the healthcare workforce and, in some cases, puts, 'black lives at risk' in comparison with other ethnic groups.

Coalition member organisation, Race Equality First, describes how racism experienced by Black and ethnic minority groups in health care derives from historical perceptions about Black and ethnic minority people's biology being 'different' to other races, such as their skin being thicker, or their nerve endings less sensitive than white people's¹⁴. However, as REF points out, there are no such differences - this is a socially constructed idea which has persisted into modern

¹⁴ <https://www.open.edu/openlearn/health-sports-psychology/health/a-matter-life-and-death-inequalities-healthcare-black-asian-and-minority-ethnic-communities>

day healthcare, continuing to fuel inadequate treatment of ethnic minority people, including delayed or sub-optimal pain management.

Research also demonstrates that women generally are not taken seriously when reporting pain. Black and ethnic minority women therefore face a double penalty, contributing to one particularly shocking intersectional health inequity: that Black women remain 4 to 5 times more likely to suffer maternal death, and Asian women twice as likely, compared to White women in the UK. Whilst this alarming statistic isn't related to gynaecological cancers, it reflects wider inequalities in gynaecological healthcare detailed in the 2019 MBRRACE-UK report¹⁵ which confirmed that reproductive conditions such as fibroids are three times more likely to occur in black women than white women, and that the misconception of endometriosis as a 'white woman's disease', had resulted in misdiagnosis and delays in appropriate treatment for black women.

Race Equality First also points out that language barriers and cultural differences can hinder ethnic minority people's access to healthcare and reports 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. REF tells us that there are occasions where children will be interpreting for family members on complex health issues, including cancer, which is entirely inappropriate.

When it comes to screening, diagnosis, and treatment of a gynaecological cancer, Coalition member organisation, Race Council Cymru describes how, to mitigate the issues experienced by black and minority ethnic people, there needs to be a multi-focused approach and collaborative effort between doctors and the Welsh Government, facilitated by the newly established Race Equality Taskforce to, 'ensure that no woman or her family suffers unnecessarily, and...address racial inequality, where it exists'.

Another group particularly at risk of experiencing barriers to optimum healthcare is disabled women – who, of course, may also be black and of an ethnic minority. Some may have physical impairments which make seeking medical help and accessing clinical settings and procedures more challenging. Others may have a

¹⁵ <https://www.npeu.ox.ac.uk/mbrrace-uk/reports>

pre-existing diagnosis of a mental health condition which many tell us prejudices their care for physical health issues, with symptoms being wrongly attributed to a psychological cause. Women with learning disabilities may have difficulties communicating their symptoms and needs or understanding their import - 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', whilst neurodivergent women experience, 'both inequitable access to diagnostic services and unequal access to healthcare more widely, including to healthcare screening such as cervical cancer screening tests'¹⁶.

Coalition member and academic, Dr Aimee Grant, described how, when reviewing evidence on the infant feeding experiences of Autistic people¹⁷, the findings highlighted that health care systems were inaccessible to Autistic people, because services are based on the assumption that patients are neurotypical. The analysis also found that variation in pain presentation and sensory differences were not understood by health professionals.

Another paper in development, where 193 Autistic people from the UK who had been pregnant answered questions about their challenges accessing all (not just maternity) healthcare, discovered barriers which would similarly apply to those seeking help for a gynaecological cancer. They included the challenges of making telephone calls to obtain an appointment and waiting rooms which induced anxiety due to the sensory environment and other patients. When being assessed by health professionals, participants noted difficulties describing their pain – indeed, miscommunication or frustration relating to communication is frequently cited as a barrier to autistic people's receipt of optimum healthcare.

Health passports, posited by NICE as a possible solution to the barriers experienced by autistic people, may not be as effective as thought. Dr Grant would like to draw the Committee's attention to a third paper, currently undergoing peer review¹⁸, which shows that health passports are, in reality, under-theorised, poorly evaluated, and unlikely to achieve much at all in terms of

¹⁶ <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf>

¹⁷ <https://journals.sagepub.com/doi/full/10.1177/13623613221089374>

¹⁸ <https://www.medrxiv.org/content/10.1101/2022.12.04.22283076v1>

reducing barriers to healthcare for Autistic people. The feasibility of using health passports within medical settings has not been explored with doctors and other health professionals, and the routine use of short consultation times is likely a significant barrier to their usability. The Coalition would therefore suggest that autistic people, the Welsh Government's Disability Rights Taskforce, and National Autism Team be involved in discussing and co-producing solutions to these issues, not least in the context of gynaecological cancer care.

Challenges also face trans men and intersex people who need to access healthcare for gynaecological issues, including cancer. The tendency to signpost people to 'women's health services' rather than 'gynaecology' not only reduces women's health just to their reproductive organs, it can also create barriers to seeking medical help or participating in screening programmes. One recent BBC report¹⁹ described how, due to his gender, a trans man who had retained his cervix encountered confusion from healthcare providers when needing to access follow-up for an abnormal cervical screening result. Meanwhile, NHS guidance says a trans man or intersex person registered with a GP as male will not usually receive automatic invitations for screening so there is clearly scope for improvement when it comes to designing processes and services that are able to meet people's individual needs.

More generally, whilst guidelines exist for identifying and managing patients reporting symptoms which may indicate a gynaecological cancer, they are not always followed. Jo's Cervical Cancer Trust described to the Coalition how more than one in four young women reporting abnormal bleeding are erroneously given a cervical screening test - which in fact slows down a diagnosis while waiting for appointments and results. Clearly, therefore, there is a need for increased awareness amongst healthcare professionals of the correct pathways for the different gynaecological cancers. For cervical cancer symptoms, this includes a visual examination.

The importance of accessible, accurate, widely available information

¹⁹ <https://www.bbc.co.uk/news/uk-england-humber-58515769>

Information and awareness of risk factors for the different gynaecological cancers across the life course and the symptoms associated with gynaecological cancers is essential.

As it stands, data tends to conflate all five gynaecological cancers under one umbrella term, which can make it more challenging to identify and accurately report on issues around patient experience. The Coalition would ask that this situation is remedied as soon as possible so that healthcare providers and the public are in a position to differentiate between the five in terms of symptom recognition and treatment pathways, patient experiences and outcomes, and latest research.

Regardless of the above, however, individuals affected by any of the five gynaecological cancers will share similar challenges in terms of gaining a timely diagnosis. Partly this is because individuals are unaware of their own risk factors, and partly because symptom recognition is poor. Unlike breast cancer, over the last 30 years, there has been no improvement in outcomes for gynaecological cancer, largely as a result of delayed diagnoses which, in turn, can be partly attributed to a lack of widely publicised, accurate, information.

Uterine (Womb) Cancer is the fourth most common cancer in females, at over 9300 individuals affected in the UK per year. Three quarters of those will be post-menopause. Obesity is a significant risk factor but, whilst increased awareness of the health risks associated with obesity is important for prevention, there needs to be a great deal more understanding of the wide-ranging causes of obesity if we are to offer person-centred support to people trying to lose weight. Another risk factor is a genetic condition called Lynch Syndrome. Key symptoms of womb cancer include vaginal bleeding after menopause, between periods, and unusually heavy bleeding. However, public discourse and understanding of what constitutes 'normal' bleeding, when to seek help, and how to ensure further investigations are undertaken is lacking. This, the Coalition hopes, will constitute part of menstrual wellbeing education in schools in Wales but advise that increased public awareness across age groups is also necessary.

Ovarian Cancer affects around 7500 individuals per year in the UK. It is the sixth most common cancer in females and has the lowest survival rate out of all the gynaecological cancers. Eight out of ten of those affected will be over 50 years of

age. There are also inherited risk factors, including the BRCA 1 or 2 gene, and being of Ashkenazi Jewish heritage. Persistent bloating, pelvic and abdominal pain, unexplained change in bowel habits, feeling full quickly or feeling nauseous during and after eating, and needing to urinate more regularly are the main symptoms. Symptoms like these can be commonly mistaken for issues like irritable bowel syndrome (IBS) and, as a result can be normalised and dismissed by both patient and professional. It is vitally important to both raise awareness of the disease's symptom profile but also to ensure that patients feel sufficiently empowered with that knowledge to persist in seeking further investigations if necessary, and for healthcare professionals in general practice, gastroenterology, and colorectal departments to be equipped to identify the disease promptly, given that IBS-like symptoms may well see patients affected in their consulting rooms.

Cervical Cancer affects more than 3000 individuals per year in the UK, mostly aged between 30 and 45 years of age. It is very rare in under-25s. 99.8% of cervical cancers are preventable and, outside of the pandemic, the UK's cervical screening programme is estimated to save over 4000 lives per year. Public awareness of cervical cancer symptoms is low, with over half (52%) of women in the UK unaware that bleeding during or after sex is a symptom. Low awareness among health professionals, particularly in primary care, can further delay diagnosis. Understanding and awareness of HPV is similarly low, with myths about who is at risk of contracting HPV, and the nature and longevity of the virus, leading some women to falsely believe that they would not benefit from attending a cervical screening. An improved understanding of HPV can facilitate understanding of HPV vaccinations and cervical screening in preventing cervical cancer, enable women to make better informed decisions about their health, and emphasise the importance and relevance of the cervical cancer prevention pathway.

Vulval Cancer is one of the rarer cancers with over 1,350 cases diagnosed in the UK each year. Around 80% of vulval cancers are diagnosed in females over 60 but more and more cases are being identified in younger patients. Inflammatory skin conditions like lichen sclerosus present an increased risk but many women are either too embarrassed to seek early intervention for this condition or wrongly dismiss it as something to be endured as part of the ageing process.

Vaginal Cancer is the least common gynaecological cancer, with just over 250 women and people diagnosed in the UK each year. 40% of those diagnosed will be over 75 years of age but it can occur at any age. The incidence of vaginal cancer has remained relatively stable over the last 25 years.

Jo's Cervical Cancer Trust informed the Coalition of enquiries they had undertaken with women in Wales who had accessed cervical screening or gynaecological services to establish their views on awareness of symptoms and wider education: 55% thought that there was some awareness about risk factors and symptoms, but there could be more. 19% think there is only a little awareness and education, while 16% say there is hardly any awareness or education.

Of course, information also needs to be accessible to a wide range of audiences. Race Equality First points out that many ethnic minority individuals get their health information from their friends and family, therefore, healthcare providers need to utilise non-traditional channels to disseminate information.

They advise:

- Working with organisations and groups who support and assist ethnic minority women on a campaign to spread awareness of HPV and cervical cancer and the importance of attending screenings (and other gynaecology-related appointments), similar to the work of the British Islamic Medical Association on combatting myths and disseminating correct information surrounding the COVID-19 vaccination
- Hold information awareness sessions: twice as many ethnic minority women as White women said better knowledge about smear tests and why it is important would encourage them to attend (30% against 14%).
- Invest in training for healthcare practitioners on how to conduct culturally appropriate screenings, i.e., understanding that women of certain ethno-religious backgrounds will likely want their smear test, or any gynaecological investigations, to be conducted by a female health practitioner. This notion is supported by research conducted by Jo's Cervical Cancer Trust: almost half (45%) of White women would be

comfortable talking to a male GP about cervical screening but only 28% of ethnic minority women agreed.

- That health practitioners ensure that Black and ethnic minority women, especially older Black and ethnic minority women, understand the information they are being given by their healthcare providers. Health care practitioners should not rely on a family member to translate on their behalf. A professionally trained and culturally appropriate interpreter should be present / available to do this.

Equally, it is important that all information is made available in a variety of accessible formats, suitable for people with different impairments such as sight and hearing loss, and literacy levels. To achieve this, it's crucial that health services record the communication preferences of people with sensory loss and other needs, to avoid missed appointments and barriers to finding out test results and receiving information on their condition and medication instructions. Likewise, it should be possible to make – and attend - appointments using different mechanisms according to people's different needs and circumstances. For some patients, independent advocates and / or care co-ordinators will also be required, to help them understand the information presented to them, make informed decisions, and navigate complex pathways.

Increasing uptake of cervical screening

Increasing cervical screening uptake is an important part of reducing and eventually eliminating cervical cancer. As of October 2021, cervical screening coverage across Wales is at 69.5%. This has declined from 73.2% reported in 2019/20. There is great variation in cervical screening coverage at Local Authority level, with a difference of almost 10% between coverage in Merthyr Tydfil (65.7%) and Monmouthshire (74.7%). Women living in high areas of deprivation are less likely to have received the HPV vaccine and are less likely to attend cervical screening. The inequity gap, the difference between uptake/coverage in the least deprived communities compared to the most deprived communities, is 12.1% for Cervical Screening Wales – a gap which has worsened in recent years. We urge

public awareness campaigns, and efforts to improve the accessibility of cervical screening, to improve this uptake.

The pandemic saw a fall in both numbers of people having the HPV vaccine and attending screening appointments, so this patient group will be at higher risk of developing cervical cancer and having it diagnosed and treated early.

Coalition members report several barriers to cervical screening, including:

- Finding the time to attend
- Inconvenient appointment slots
- Previous bad experiences and trauma
- Worries about pain
- Embarrassment
- A physical impairment
- Personal anxieties.

Two-thirds of physically disabled women have been unable to attend screening and almost half of survivors of sexual violence have not attended. Women living in poorer areas are less likely to attend while 80% of women in full-time work struggle to get a convenient appointment.

It is widely acknowledged that Black and ethnic minority women are less likely to attend cervical screenings than White women²⁰. 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 age²¹.

One 2015 study²² reported that ethnic minority women felt there was a lack of awareness about cervical cancer in their community. This study highlighted the barriers to cervical screening as emotional (fear, embarrassment, shame), practical (lack of time) and cognitive (low perceived risk, absence of symptoms). Low perceived risk of cervical cancer was influenced by beliefs about having sex

²⁰ <https://srh.bmj.com/content/41/4/248>

²¹ <https://www.iostrust.org.uk/about-us/our-research-and-policy-work/our-research/cervical-screening-among-bame-communities>

²² <https://srh.bmj.com/content/41/4/248>

outside of marriage; some women felt a diagnosis of cervical cancer might be considered shameful. Furthermore, the physical process of having a smear test is a barrier within itself for those from certain cultures, as the act is seen as improper. The influence of culture and religion can therefore play a part in explaining why people may not have correct information about HPV, cervical cancer, and associated screening²³.

Research undertaken by Jo's Cervical Cancer Trust in the context of the pandemic revealed that four in 10 women from an ethnic minority background 'would feel unsafe' attending a doctor's surgery because of COVID-19, with Black, Asian and minority ethnic women twice as likely (20%) to be strongly worried about contracting the virus at a cervical cancer screening than white women (9.4%). They were also almost twice as likely than white women to strongly agree with the need for more information about safety measures in place at a screening appointment and that 'knowing other people who have been screened and felt safe would make them more likely to have a smear test if it was due'.

Workforce pressures in primary care, and limited options of where and how to access screening, are significant challenges. Most tests are performed at GP practices, with some provision at sexual health clinics. For those who need to travel a distance to their GP, those with full-time work or childcare commitments, and physically disabled women, the lack of choice in where to access screening can be prohibitive.

A survey carried out by Coalition member organisation, the National Federation of Women's Institutes (NFWI) found that 22% of those aged 50 to 64 in Wales had not attended cervical screening since the age of 50. The findings highlighted that uptake of cervical screening amongst people over the age of 50 could be improved by, for example, promoting greater awareness of the risks of cervical cancer and benefits of screening to this demographic, and ensuring greater understanding about how cervical screening can be made easier after the menopause.

To improve uptake more generally, providers should work on improving the availability and flexibility of screening times and locations to make it as easy as possible for women to attend an appointment, including out-of-hours and at

²³ <https://srh.bmj.com/content/41/4/248>

weekends. Women should be able to attend walk-in screening appointments at a sexual and reproductive healthcare service, a community clinic, or a mobile screening clinic. All cervical screening providers should offer text reminders to those due cervical screening, and there should be investment made in increasing awareness of cervical screening, what to expect from the test, and the options that are available to make it easier.

HPV vaccination is a vital tool in preventing cervical cancer, so it is vital that any consideration of inequalities and barriers extend to this too. Vaccine hesitancy and low understanding around the HPV vaccine are barriers to vaccine uptake. Some groups are particularly likely to have a lower uptake of the HPV vaccine, including those living in areas with high levels of social deprivation, some ethnicities, and those previously excluded or not in school. Among parents of soon-to-be eligible children, just 55% are aware of HPV and the girls' HPV vaccination programme. Coalition members believe that everyone should have appropriate information and increased awareness across the life course about what HPV is, how common it is and what it means to have the virus. Including age-appropriate information about HPV in mandatory RSE lessons would be welcomed. Additionally, greater parental awareness of HPV and the vaccine has been shown to have a positive impact on decisions to vaccinate children, with low awareness or understanding among healthcare professionals also a barrier to uptake.

More opportunities to catch up on vaccinations is needed to improve the performance of the immunisation programme. The move to a one dose schedule of the vaccine means it is more important than ever to know who has received the vaccine and ensure that there are ample catch-up opportunities so that nobody misses out on its protection.

The Coalition felt that addressing stigma around HPV was essential, so that people feel able to talk about it and aren't deterred from attending cervical screening. One option in future for helping increase uptake of cervical screening could be the offer of HPV self-sampling, with evidence suggesting that there is considerable support for such provision. However, we recognise that carrying out HPV self-sampling in the privacy of one's home may not be for everyone's choosing.

The Coalition would support calls for further research and pilot studies to help build a strong evidence base for the introduction of HPV self-sampling in the most effective and accessible way. The option of self-sampling should be made available as early as possible once this evidence base is in place. It is also fundamentally important that programmes of this nature are co-produced so that people's questions, concerns, and experiences are taken into account throughout. Further research on the benefits of extending the upper age of cervical cancer screening beyond 64 would also be welcomed.

Alongside practical considerations like the above, the Welsh Government must also focus on understanding and addressing the barriers to screening amongst currently underserved groups known to be less likely to attend cervical screening, such as women from ethnic minority groups or more deprived areas. While COVID-19 has brought in additional barriers to attending either screening or other appointments necessary to make a prompt diagnosis and expedite treatment of a gynaecological cancer, we cannot forget that the wide range of barriers that existed before the pandemic, including psychological, cultural, physical and literacy, have not gone away. Reasons for non-attendance are variable and complex, and solutions must be co-produced with those affected, alongside improving mechanisms for gathering and disaggregating data on screening uptake.

Faster diagnosis of ovarian cancer

Over 300 women are diagnosed with ovarian cancer each year in Wales and more die because of ovarian cancer each year in the UK than all other gynaecological cancers combined.

The four main symptoms of ovarian cancer are persistent stomach pain, persistent bloating, difficulty eating/feeling full more quickly and needing to wee more frequently. Other symptoms of ovarian cancer can include persistent indigestion or feeling sick, pain during sex, a change in bowel habits, back pain, feeling tired all the time and unintentional weight loss.

The earlier ovarian cancer is diagnosed the easier it is to treat. Ovarian cancer is tricky to diagnose because the symptoms are easily mistaken for less serious

health problems, such as Irritable Bowel Syndrome (IBS) and Premenstrual Syndrome (PMS). As a result, it is often not diagnosed until it has spread, and a cure not possible.

Overall awareness of the symptoms of ovarian cancer remains low. Research published by Target Ovarian Cancer in 2022 revealed that only 27% of women in Wales were able to name bloating as a symptom, 33% abdominal pain, 3% feeling full and just 2% urinary urgency, yet awareness is crucial to early diagnosis, not just on the part of women but also healthcare professionals. Whilst there remains no screening tool for ovarian cancer, it is of the utmost importance that clinicians take the necessary steps when women present with symptoms.

Early diagnosis means that treatment can be started earlier when it is mostly likely to be effective: 95 per cent of women diagnosed at stage 1 are expected to survive for one year or more, compared to just 48 per cent of those diagnosed at stage 4. Prior to the coronavirus pandemic, only 37% of women with ovarian cancer in Wales were diagnosed at an early stage. Our concern is that, following the pandemic, these figures will be even lower, with women less likely to seek help due to worries about COVID-19, and other challenges in accessing healthcare in a timely manner.

As it stands, waiting times for ovarian cancer treatment are amongst the longest in the UK. Improvements in primary care and secondary care diagnostic pathways for ovarian cancer are essential to ensure women access care quickly. Members of the Women's Health Wales Coalition would like to highlight the work of the ongoing Ovarian Cancer Audit Feasibility Pilot²⁴ and urge the Welsh Government to implement insights and best practice to improve diagnostic pathways within secondary care.

We would also emphasise the importance of identifying and addressing disparities in ovarian cancer diagnosis and treatment, including:

- Ethnic disparities in referral to treatment times, with the RCOG reporting that Black and Asian women wait five to six days longer on average than white women.

²⁴ <https://targetovariancancer.org.uk/get-involved/campaign/policy/ovarian-cancer-audit-feasibility-pilot>

- Disparities in diagnosis by area of deprivation, with women living in the most deprived areas up to 50 percent more likely to die within two months of diagnosis than those in the least deprived.
- Geographical variation in early diagnosis, access to surgery and treatment varying between regions
- Disparities by age, with women over 70 more likely to be diagnosed via emergency presentation rather than planned care.

Coalition members would urge the Welsh Government and Public Health Wales to commit to continued and sustained investment in awareness campaigns featuring the signs and symptoms of ovarian cancer.

Diagnosing Uterine (Womb) Cancer

A hysteroscopy will usually be a first step in diagnosing uterine cancer. It is a procedure used to examine the inside of the womb (uterus), involving a rigid knitting needle-like rod with a tiny camera and surgical tools being passed through the cervix into the womb. The procedure ranges from diagnostic hysteroscopy with biopsy to detect cancer to operative removal of polyps and small fibroids.

A hysteroscopy is now usually carried out on an outpatient or day-case basis, with procedures lasting anywhere between 10 minutes to more than half an hour. Often, anaesthetic is not provided. The NHS website²⁵ describes the experience of pain during hysteroscopy as ‘vary(ing) considerably between women. Some women feel no or only mild pain during a hysteroscopy, but for others the pain can be severe’. The website goes on to advise patients that, ‘If you find it too uncomfortable, tell the doctor or nurse. They can stop the procedure at any time. If you're worried, speak to the doctor or nurse before having the procedure about what to expect and ask them about pain relief options’. The Coalition’s members are concerned that this advice does not reflect their research into patients’ experiences, either in terms of individual pain scores or in terms of the information, support, and options that are offered.

²⁵<https://www.nhs.uk/conditions/hysteroscopy/>

A survey conducted by one of the Women's Health Wales member organisations, Hysteroscopy Action, has collected 3,000+ accounts of extreme pain, fainting and trauma during outpatient hysteroscopy²⁶ and found that women are routinely having womb endoscopy in NHS outpatients with no sedation but only ibuprofen from home and 'distraction technique'. The reliance on a 'vocal local' (patients being expected to verbalise pain and the need to stop, rather than medical analgesia and anaesthetic) puts those with learning disabilities, selective mutism, speech impediments, or with limited English or Welsh at an even more significant disadvantage.

Research by the Royal College of Obstetricians and Gynaecologists reveals that 1 in 3 women having outpatient hysteroscopy will experience severe pain²⁷. However, Hysteroscopy Action's survey suggests that women are not necessarily being informed of this possibility or, indeed, of the options available to them. It also shows that some women being advised to have hysteroscopy whilst awake should not have been candidates for various medical reasons, including no previous vaginal delivery, or having had previous cervical surgery.

Various NHS audits suggest that a lack of day-surgery theatre space and sedation services adds to the problem²⁸, despite NHS website information advising women that the use of general anaesthetic will be facilitated, should that be their preference. Indeed, a statement on the RCOG website instructs gynaecologists to give women the choice of being awake or asleep for quick day case surgery²⁹. However, as recently as June 2022, a report in The Health Service Journal described significant numbers of women not being offered the choice to have either general anaesthetic or sedation, often due to staff shortages³⁰.

Last year the NHS launched a new programme called Getting it Right First Time (GIRFT) now being rolled-out in Wales, which has set a target driven by the British Association of Day Surgery for the NHS to do 90 percent diagnostic and 50

²⁶ www.hysteroscopyaction.org.uk

²⁷ <https://s3-eu-west-1.amazonaws.com/ddme-psl/gpp-standards-in-outpatient-hysteroscopy-draft-peer-review.pdf>

²⁸ <https://www.patientsafetylearning.org/blog/guidance-for-outpatient-hysteroscopy-consultation-response>

²⁹ <https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/hysteroscopy-best-practice-in-outpatient-green-top-guideline-no-59/>

³⁰ <https://www.hsj.co.uk/patient-safety/staff-shortages-leaving-women-in-barbaric-pain/7032543.article>

percent operative womb endoscopies without general anaesthetic or sedation³¹. Whilst cost-saving measures are often to be welcomed (ablation of the womb lining carried out in such a way could save as much as £1000 per patient), the Coalition is most concerned that reducing cost in this instance should not jeopardise genuine patient choice. It is important that patient reported experience and outcome measures are collected, as well as patient trajectories as, although outpatient hysteroscopy can improve efficiency and reduce waiting lists in the first instance, there is a risk that traumatised patients will delay future help-seeking (one reason given for low uptake of cervical screening) and / or need mental health support subsequently.

The Coalition recognises that the need to reduce escalating gynaecology waiting lists is urgently required. However, this must not be at the expense of properly informed consent, patient experience, and wellbeing. More day-surgery theatre space is needed, as is safely monitored IV sedation with analgesia for women's endoscopy (hysteroscopy), much like that offered for patients undergoing colonoscopy and gastroscopy.

End of life care for women and people with a gynaecological cancer diagnosis

Improving prevention and treatment of gynaecological cancers is a vital part of ensuring women and those assigned female at birth (AFAB) are living well for longer. However, it is also important to recognise that some gynaecological cancer diagnoses are terminal. Where this is the case, we need to ensure that the best end of life experience possible is achieved, in line with the person's wishes and preferences, and that no disproportionate barriers are facing women when they need end of life care and support. Therefore, the Women's Health Wales Coalition would urge the Health and Social Care Committee to consider palliative and end of life care (PEOLC) throughout this inquiry and that its evidence-gathering takes a truly cradle-to-grave approach.

Research exploring gender inequalities at end of life is still fairly limited, particularly in relation to the situation in the UK and in Wales. As a result, this response will put forward the challenges facing women with a terminal illness

³¹ <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/Maternity-and-Gynae-Sept21L.pdf> p.72

more generally, many of which will apply to those with terminal gynaecological cancer.

According to Coalition member organisation, Marie Curie Cymru, annual deaths and demand for PEOLC is set to increase drastically over the next two decades. By 2040, annual deaths in Wales and England are projected to rise by 25.4% (from 501,424 to 628,659), with demand for palliative care set to increase by 42%. This is partly due to an ageing population and a rise in the number of people living with more than one complex condition. All this points towards an increasing number of women in need of PEOLC in the imminent future and, with 546 females dying from gynaecological cancer in 2021 alone, it is crucial that the Committee's inquiry includes a focus on women with a terminal diagnosis.

There are various challenges faced by women at end of life according to international research:

- Pain management and symptom burden

Recent Marie Curie research asked people in Wales what their biggest priority would be when thinking about the end of their life; being pain free was most people's top answer. One of the key pillars of PEOLC is a focus on quality of life and pain management, as being pain free enables people to experience a good quality of life for as long as possible. However, research shows that there are factors relating to sex and gender which have led to discrepancies in how some women report symptoms, the pain they experience, and the treatment they receive as they approach end of life.

Evidence shows that 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. Research 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. As already mentioned in this Coalition response, there is also evidence to show that women are more likely to have pain attributed to psychological rather than physical causes and to then be prescribed sedatives rather than the appropriate pain relief. The gender bias at play when it comes to how women and men are expected to cope with symptoms can directly affect some women's access to pain

management medications, meaning some women may be suffering from unwarranted pain and severe unmet palliative care needs when approaching the end of their life.

Biological differences when it comes to how females and males experience pain and respond to pain management is not a new phenomenon, but research now suggests that this could negatively impact women right up until their death. 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. However, more research is needed here to fully understand how women could be responding to end of life pain management differently to men, to ensure no one is suffering from avoidable pain in their last months, weeks, and days of life.

- End of Life Care Interventions

PEOLC 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 . When it comes to choices around end-of-life care interventions, the understanding and views of women appear to be affected by social norms and gender bias. While some research shows that terminally ill women tend to be more open, accepting of palliative support, and engaged with their end-of-life journey, other studies show that some women are less likely than men to state a preference for end-of-life care treatments such as chemotherapy, cardiopulmonary resuscitation, and artificial feeding. The evidenced reasons behind this are not yet substantive and should be fully explored, however such findings do highlight potential inequalities in the way women are approaching, deciding on, and ultimately accessing treatments which could improve their quality of life.

One example of this is how females may not be benefitting from early palliative care (EPC) in the same way as males . EPC is believed to be best practice and is attributed to better quality of life and lower rates of depression, but findings have shown that females in some instances report lower quality of life and mood than male counterparts receiving similar treatment .

End of life care clinical decisions continue to rely on research and assumed best practice which is majorly based on male biology, neglecting any potential differences in sex and gender. To ensure everyone can access the EOLC interventions which will benefit them and enable a better quality of life for longer, more research is needed into how sex and gender impacts on care and treatment decisions.

- Place of care and death

We know that over half of all people would prefer to die at home , but research suggests that for many women this is often not possible or the case. Social norms have dictated a society where it is women who are the natural caregivers and many even feel it is their duty when it comes to providing care . Nonetheless, many women express fears around feeling like a burden if they themselves need care from family and loved ones. In fact, studies report more women receiving care and support from healthcare professionals and specialists rather than unpaid carers.

The fact that women have longer life expectancy and are more likely to outlive their partner (in a heteronormative relationship), reinforces this trend. Additionally, those who have been carers (of which the majority are women) are less likely to want to die at home. This is assumed to be due to a greater understanding of the reality of caring for someone at home.

A wider challenge in supporting women to die at home if this is their preference, is insufficient resources and capacity in health and social care community provision. Recent research projects a substantive increase in demand for care in the community by 2040 in Wales and England, with deaths at home increasing by 88.6%, and deaths in care homes projected to increase by as much as 108%. 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.

Research and data

Ample evidence exists that patients want to participate in research trials, that patients participating in research have better outcomes, and that centres with greater research recruitment deliver better outcomes for patients. Making research participation one of the peer review measures and Quality Performance Indicators for every cancer service provider, as outlined by the British Gynaecological Cancer Society, will greatly improve translation of research into practice.

Health Boards in Wales must ensure clinicians have the time and flexibility to undertake research alongside their clinical work by factoring it into their job plans, and guarantee sufficient resourcing and support are in place for those wishing to facilitate and participate in research activities. The Women's Health Strategy for England makes clear its commitment to encouraging research into cancers so we would urge Wales to do the same. We would also call for investment in research looking at effective interventions for women from deprived communities and / or with protected characteristics, improving diagnostic tests and treatments, and the impact of treatment on improving overall quality of life.

The Coalition recommends that health data collected on gynaecological cancers is disaggregated according to type, given the differences in diagnosis and treatment between various gynaecological cancers. It is frustrating when gynaecological cancers are reported on together or referred to under the same umbrella. Each cancer has different symptoms, treatment pathways, and affect different demographics. It is also vital 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.

To bring about change in policy delivery, people's lived experiences need to be taken seriously and their voices heard. There is a lack of research into health conditions that disproportionately impact women and ethnic minority groups and a lack of evidence on the experiences and outcomes of people with protected characteristics in accessing healthcare. A proper intersectional evidence base is needed, fully disaggregated, and made publicly available in Wales.

Furthermore, research must no longer be conducted in silos – intersectional research, which incorporates appropriate intersectional methodologies (both

quantitative and qualitative) is required. There is a need for greater trust between policy makers, those whom the policy impacts, and the organisations who assist, support, and advocate for those impacted. Resources and funding will be crucial here to ensure meaningful partnerships, especially with small organisations and charities who work with minority groups.

With regards to specific research topics, the Coalition would highlight the following as being of key importance:

- HPV vaccination and access to timely screening services, including consideration of the inequalities and barriers that exist in uptake among different groups. Clinically, there are gaps in knowledge about many areas of cervical cancer. Addressing these will help prevent more cancers as well as providing answers and reassurance for women affected. This includes predictors or risk factors for persistent or recurrent HPV infections and cervical cell changes, and the cause of non-HPV cervical cancers. Research into therapeutic vaccines is also in its infancy. The successes of the existing HPV vaccination programme should give us hope for what future advances could bring.
- The development of new kind of tests - that may be less invasive, more effective, or less frequent – could make screening more accessible to many. There may be a need to explore whether current screening intervals and eligibility parameters remain appropriate, as some modelling suggests cervical cancer incidences could increase in older women over the next two decades.
- 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.
- 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.
- Exploration of how women experience end of life pain management differently to men
- Gendered choices around end-of-life care interventions and place of death. It is worth pointing out that Marie Curie Cymru is currently researching any potential gender differences in access to its services across Wales; diagnosis and reason for admission are two of the many variables being analysed and may be useful and relevant to the inquiry into gynaecological cancer. Findings are expected to be published in early 2023. Further, the Marie Curie Palliative Care Research Centre at Cardiff University is working on developing a PEOLC data dashboard. This is likely to be public in 2023 and will be able to provide data on how patients with gynaecological cancer interacted with end-of-life care services in their last year of life. The Committee should contact the Women's Health Wales Coalition and / or Marie Curie Cymru for further information on these projects.
- Applied health research will be crucial for developing better communication methods, reducing barriers, and developing more user-centric and streamlined programmes.
- Access to data relies in part on the systems in place. Robust IT systems across the pathway are an essential part of this, and this is currently lacking in Wales.

Priority given to planning for new innovations

In June 2022, Bevacizumab (Avastin) was approved for use in Wales for recurrent or metastatic cervical cancer. This was a huge win for campaigners and patients,

as Wales had previously been the only UK country not offering the potentially life-prolonging drug. Avastin was added to the Cancer Drugs Fund in England in 2014 and has been available in Scotland and Northern Ireland, for several years.

Avastin is currently the only targeted drug treatment for advanced cervical cancer. Only a small proportion of patients with advanced cervical cancer are eligible to receive it, because common side effects of the disease – such as vaginal bleeding – means the drug is not always safe for them.

The Coalition would urge the All-Wales Medicine Strategy Group to accelerate approval for advanced cervical cancer drugs, as it is unfair that women in Wales had to wait so much longer for the availability of Avastin. A new drug, Pembrolizumab (Keytruda), is currently being for use by NICE and the Scottish Medicines Consortium and we urge the AWMSG to make Pembrolizumab available routinely for women receiving treatment for advanced cervical cancer. It would be useful if the Committee were able to add its collective voice to calls for equal access to such medicines in Wales.

HPV-self sampling is recognised as an opportunity to make cervical screening more accessible and increase uptake of the test. Work in the UK around HPV self-sampling has been ongoing for many years with studies and pilots including PaVDaG in Scotland, and YouScreen and HPVvalidate in England. The Welsh Health & Social Care Committee should consider how self-sampling might be embedded into the national screening programme, if recommended by the UK National Screening Committee.

The Coalition is also aware of research underway in Wales to develop and implement an algorithm which would make symptom attribution in Ovarian Cancer more accurate, given limitations to current NICE guidance on symptom recognition. There is also the possibility of a single blood test early in the patient journey to expedite diagnosis and treatment. We would like to see more investment in this sort of research and for the results to be made widely known and implemented across Wales. The Committee's support for this kind of activity, and ongoing scrutiny of actions taken in Wales to deliver evidence-based improvements for patients would be welcomed.

In conclusion

Looking at the bigger picture, it is important to note that health inequalities cannot be unpicked unless a structural and intersectional approach is adopted in doing so and unless we see governments acknowledging structural racism, ableism, and inequality that currently exists in society.

We must not separate health inequalities from wider inequalities but, instead, look at how to dismantle inequality from a more structural perspective. For example, we know that the ethnic disparities in COVID-19 deaths are a result of the structural inequalities and racism ethnic minority people face, rather than their genetic ability to fight a virus. Ethnic minority people are over-represented in occupations where there is high risk of contracting COVID-19, for example in health and social care, in transport and in retail. They are also more likely to live in over-crowded housing and in poverty-stricken areas, putting them at greater risk of catching the virus. Before the pandemic, ethnic minority people were less likely to have access to high-quality health care, nutritious food, secure housing, and clean air. It is a similar story for disabled people, with 68% of deaths due to COVID-19 in Wales recorded as being amongst disabled individuals. These were not necessarily due to any underlying clinical vulnerability but other factors, including shared and / or poor accommodation, poverty, and barriers to seeking or receiving healthcare.

When it comes to reducing health inequalities amongst patients, we should also consider the demographics of our healthcare professionals and policy-makers. There is an under-representation of ethnic minority staff in senior roles, and an over-representation of ethnic minority staff in lower-paid roles. This is particularly apparent across NHS trusts and health boards in the UK. In Cardiff and the Vale University Health Board (CAVUHB), only 3.8% of staff in bands 7 through to 9 are from an ethnic minority, despite the ethnic minority population of Cardiff and the Vale of Glamorgan – as well as the proportion of CAVUHB's workforce that are ethnic minority – being almost three times higher at just over 10%. In addition, there are no ethnic minority CEOs of NHS health boards in Wales and only 35 Black female professors in the UK. We need to reverse the tide here to see change.

There are enormous challenges in collecting accurate data on disabled people's representation in the health and social care workforce, not least because stigma and fear of discrimination often deter people from declaring disability status. However, we know that there is a significant employment and wage gap amongst disabled people, so it is likely that they are not well-represented within the higher echelons of health and social service provision. The result is that the views, needs, and priorities of people with protected characteristics are not fully considered in decision-making, whether that be investment in health research, clinical trials, or prioritisation of services – gynaecological cancers are just one example of where a more intersectional and co-productive approach is needed.

It is clear that the issues that exist in education, employment and housing need to be addressed alongside healthcare to bring about the change that is needed to improve access to healthcare and health outcomes for ethnic minority and other marginalised groups: gynaecological cancer is one area where this intersectional approach would pay dividends.