

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](#)

GC 03

Ymateb gan: | Response from: National Federation of Women's Institutes-Wales

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## **National Federation of Women's Institutes-Wales**

### **Response to the Health and Social Care Committee consultation on gynaecological cancers**

#### **Background**

The WI is the largest voluntary women's organisation in the UK with over 190,000 members in 5,500 WIs across England, Wales, and the Islands. In Wales, there are about 14,000 members belonging to close to 500 WIs.

Health and wellbeing has always been a key priority for the WI with numerous health-related mandates dating back to its inception on issues ranging from maternal health and endometriosis to family planning and osteoporosis. Through its campaigns, the WI aims to empower women to take responsibility for their own health through education and equal access to information and facilities.

Our response to this consultation focuses on cervical screening and ovarian cancer awareness as we currently have campaigns relating to these areas. The NFWI's See the Signs campaign focuses on raising awareness of the subtle signs and symptoms of ovarian cancer to help ensure more women get a diagnosis at the earliest possible opportunity. The 5 Minutes that Matter campaign seeks to raise awareness of the importance of attending routine cervical screenings, and support more women to make an informed decision about whether or not to take up their invitations.

#### **Ovarian Cancer**

Over 300 women are diagnosed with ovarian cancer each year in Wales<sup>i</sup> and more die as a result of ovarian cancer each year in the UK than all other gynaecological cancers combined. According to Cancer Research UK, there are around 7,500 new ovarian cancer cases in the UK each year, and 4,200 deaths.<sup>ii</sup>

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 other more common and less serious health problems. As the early signs of ovarian cancer are similar to conditions such as IBS and PMS, it is often not diagnosed until it has spread and a cure is not possible.

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.

Overall awareness of the symptoms of ovarian cancer remains low, yet this is crucial to early diagnosis, alongside other factors such as healthcare professionals taking the necessary steps when women present with them.

Survey findings 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.

Confusion between cervical cancer and ovarian cancer is also a concern with some believing that cervical screening can detect ovarian cancer. Target Ovarian Cancer has found that 40 per cent of women in the UK think cervical screening detects ovarian cancer.<sup>iii</sup>

Early diagnosis means that treatment can be started earlier when it is mostly likely to be effective. 97 per cent of women diagnosed at stage 1 are expected to survive one year or more, compared to just 43 per cent of those diagnosed at stage 4.<sup>iv</sup> Prior to the coronavirus pandemic, only 37% of women with ovarian cancer in Wales were diagnosed at an early stage.<sup>v</sup>

As part of the See the Signs campaign, the NFWI has been gathering case studies of WI members' and their family members' experiences of ovarian cancer. Some members also shared their stories at the NFWI-Wales Annual Conference in March 2022 during a session about ovarian cancer:-

A WI member told us that her daughter died of ovarian cancer at the age of 48. Her daughter had felt tired and the bloating she experienced had been attributed to the menopause. She went to the doctor and was given a CA125 blood test immediately but it was too late as she was at stage 4.

A WI member told us that a family member had all the symptoms of ovarian cancer. After two years back and forth to the doctor, a huge tumour had been identified. The family member had recovered and was still doing well today.

NFWI-Wales would like to see the Welsh Government develop a public awareness raising campaign with the aim of educating the public and health professionals about the subtle signs of ovarian cancer to help ensure that more people are diagnosed early. As there is no screening programme for ovarian cancer, it is vital that action is taken to educate everyone about the symptoms and to empower women to discuss concerns with their GP.

As part of the WI's See the Signs campaign, WI members are being empowered and supported to have conversations with friends and family about their own and their loved one's health, focussing on possible signs and symptoms of ovarian cancer. WI members are also using their strong community links to reach more people with the vital messages on spotting the early signals of ovarian cancer. The NFWI has created posters and leaflets highlighting the four main symptoms of ovarian cancer which members can display in their local communities. The See the Signs campaign will also work alongside healthcare professionals to help ensure that they are also aware of the relevant symptoms and can make a referral when necessary.

## **Cervical screening**

Around 160 women are diagnosed with cervical cancer every year in Wales.<sup>vi</sup>

The number attending cervical screening has fallen in recent years. As of October 2021, screening coverage was 69.5% across Wales.<sup>vii</sup> This is a decrease from 73.2% in 2019/20, 76% in 2017/2018 and 77% in 2016/17.

Attendance is lowest amongst those aged 25 and 29 at 63.4%<sup>viii</sup> yet cervical cancer is the most common cancer among women under the age of 35. Other frequent non-attenders include ethnic minorities, people from lower socio-economic groups, women with learning disabilities and lesbian and bisexual women.

To help improve cervical screening attendance, there is a need to raise public awareness of the cervical screening programme and why it's importance to improve uptake.

Between August and October 2020, the NFWI carried out a survey to understand attitudes towards cervical screening and sampling methods in England and Wales with the aim of improving uptake. All women and people with a cervix aged 25 and over were invited to take part and there was no upper age limit.

### **Public awareness of the basic science behind cervical cancer**

Our research found that there is a need for improved education and public awareness of HPV. 53% of respondents in Wales aged 25 to 64 were unaware that the screening programme had changed to HPV-first testing in 2018.

There is also a need to address the stigma around HPV so that people feel able to talk about it and aren't deterred from attending cervical screening. If tested positive for HPV, 11% would not feel comfortable discussing it with their family or with their friends. Just over 20% were undecided.

### **Barriers to cervical screening and strategies to improve uptake of cervical screening**

Our research focused on barriers to cervical screening and strategies to improve uptake. Finding the time to attend routine cervical screening was a key barrier among respondents aged 25 to 49. Other reasons included bad experiences, inconvenient times, worries it would be painful, embarrassment, a physical disability and personal anxieties.

22% of respondents in Wales aged 50 to 64 had not attended cervical screening since the age of 50. This highlights that uptake of cervical screening amongst people over the age of 50 could be improved by, for example, greater awareness of the risk of cervical cancer and the benefits of screening to this demographic and greater awareness about how cervical screening can be made easier after the menopause.

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

In light of the above findings, strategies that could help address some of the barriers to attending routine cervical screening and increase uptake are outlined below:

- Increased public awareness of the option of evening and weekend appointments where these are available at GP surgeries;
- GPs to consider offering cervical screening appointments at different times of the day, where capacity allows if this is not currently an option;
- All cervical screening providers to implement text reminders to those due cervical screening;
- Increased awareness of cervical screening, what to expect from the test and the options that are available to make it easier.

### **HPV self-sampling**

One option in future for helping increase uptake of cervical screening could be the offer of HPV self-sampling. Our research found that there is considerable support for the option of HPV self-sampling among those who are eligible for cervical screening. 43% of those eligible for screening in the 25 to 64 age group and 60% of respondents aged 65 and over in Wales told us that they would in future prefer the option of taking the test at home using a self-sample kit. However, we recognise that carrying out HPV self-sampling in the privacy of one's home may not be for everyone's choosing.

The NFWI is supportive of 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. We would like to see Public Health Wales make the option of self-sampling available as early as possible once a strong evidence base is in place and it has been recommended by the UK National Screening Programme. It will be vital that people's questions, concerns and experiences are taken into account in the development of a self-sample test for HPV.

### **Extending the upper age of cervical screening beyond 64**

Respondents to our survey were overwhelmingly positive about attending routine cervical screening past the current upper age limit if this were to be made available. We would therefore be supportive of further research on the benefits of extending the upper age of cervical cancer screening beyond 64.

### **Women and Girls' Health Plan for Wales**

We welcome the Welsh Government's commitment to develop a Women and Girls' Health Plan for Wales to address the health inequalities that disproportionately impact women, girls, and people assigned female at birth.

A section relating to 'Cervical Screening and Cell Changes' was included in the report launched by the Women's Health Wales coalition in May 2022.<sup>ix</sup> The section included recommendations to address issues such as barrier to cervical screening, awareness of HPV and gaps in research and we hope very much that these recommendations will be considered during the development of the Welsh Government's Women and Girl's Health Plan.

In addition, we hope that the Plan will focus on other gynaecological cancers including ovarian cancer. As highlighted above, it is vital that there is greater awareness of the signs of ovarian cancer amongst the public and health professionals in order to help increase early diagnosis.

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<sup>i</sup> <https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/cancer-incidence-in-wales-2002-2019/>

<sup>ii</sup> <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer>

<sup>iii</sup> <https://targetovariancancer.org.uk/news/do-enough-us-know-symptoms-we-investigate>

<sup>iv</sup> <http://www.wcisu.wales.nhs.uk/cancer-survival-by-stage-at-diagnosis-in-1>

<sup>v</sup> <https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/cancer-incidence-in-wales-2002-2019/>

<sup>vi</sup> <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence#heading-Zero>

<sup>vii</sup> <https://phw.nhs.wales/news/men-younger-people-and-those-living-in-the-more-deprived-communities-in-wales-show-lower-uptake-of-life-saving-screening-services1/screening-division-inequities-report-2020-21/>

<sup>viii</sup> <https://phw.nhs.wales/news/men-younger-people-and-those-living-in-the-more-deprived-communities-in-wales-show-lower-uptake-of-life-saving-screening-services1/screening-division-inequities-report-2020-21/>

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