Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Canserau gynaecolegol

This response was submitted to the Health and Social Care Committee consultation on Gynaecological Cancers

GC 14

Ymateb gan: Tenovus | Response from: Tenovus

Response to Gynaecological Cancers Inquiry Call for Evidence

March 2023

Tenovus Cancer Care is one of Wales's leading cancer charities, with a long and distinguished history of providing practical and emotional support to everyone affected by cancer in their community.

We are committed to working alongside people affected by cancer to champion their needs, raise awareness of the issues faced and ultimately improve cancer outcomes.

General comments

Thank you for this opportunity to provide evidence to the Health and Social Care Committee (the Committee) concerning gynaecological cancers in Wales. Tenovus Cancer Care does not represent or prioritise any one type of cancer over any other, we are a generalist cancer charity providing support services to anyone with any kind of cancer. Our response reflects this position. For specific tumour-related responses we defer to those tumour-site specific charities and their particular areas of expertise and insight.

Where web-based resources are referred to, we have supplied a hyperlink towards the end of this response.

We welcome the steps taken by the Committee to capture the testimonies of women across Wales with a gynaecological cancer experience. Through the course of this evidence-gathering period we have heard concerning, and at times harrowing, stories from women who have felt ignored, their dignity compromised and left with distressing feelings at an already overwhelming time of their lives.

Where we have been able to do so, we have referred women onto the Senedd's engagement team who have managed the capturing of stories on film. We trust that Committee members will reflect on these testimonies with compassion and are able to reach findings that will help to ensure that women found in similar situations in the future do not experience similar outcomes.

We encourage Members to speak to clinicians involved in the diagnosis, treatment and care of women affected by gynaecological cancers, in particular the clinical lead

of the gynaecological cancers site group[i], Dr Louise Hanna at Velindre Cancer Centre.

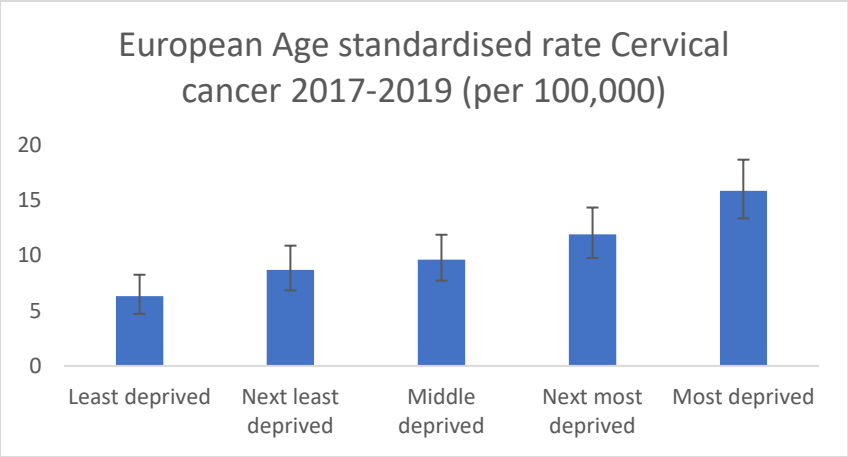
Incidence of gynaecological cancers in Wales

2019 (most recent data):
There were 981 cases of gynaecological cancers in Wales, 145 of which were cervical cancers, 306 ovarian and 530 uterine.

Together these cancers accounted for 10% of all cancers in women in Wales in 2019 (981/9515). This makes gynaecological cancers (as a group) the 4th most common cancer type amongst women.

Betsi Cadwaladr UHB had the highest incidence numbers of all gynaecological cancers, due to the size of the health board and it also had the highest European age standardised rate of cervical cancer (due to deprivation links).

Although there is a trend for increased incidence rates for ovarian and uterine cancers associated with increased deprivation, these trends are not statistically significant, whilst cervical cancer incidence rates are significantly affected by deprivation.



Cancer mortality

Sadly in 2021, 373 women in Wales lost their lives to gynaecological cancers, this was made up of 50 deaths from cervical cancer, 203 from ovarian cancer and 120 from uterine cancer, making ovarian cancer the deadliest of the gynaecological cancers.

Gynaecological cancers accounted for 9% of cancer deaths in women in Wales in 2021 making it the 4th most common cause of cancer death in women.

Deprivation and gynaecological cancers

As mentioned, cervical cancer is strongly associated with deprivation, due in part to smoking rates, earlier onset of sexual activity (and potential HPV exposure) and obesity.

When the mortality rates for the least deprived areas in Wales are applied to the numbers of deaths in the other areas in Wales, it is apparent that as many as 28 cervical cancer deaths a year in Wales are associated with deprivation.

However, as cervical cancer is largely preventable through the detection of pre-cancerous cells during cervical screening, much of this inequality is to do with screening uptake.

Response to the Committee's Terms of Reference

> *The information available and awareness about the risk factors for gynaecological cancers across the life course and the symptoms associated with gynaecological cancers.*

We believe there needs to be more information available at every stage of a woman's life to better inform them of the signs and symptoms of gynaecological cancers over the course of their lifetime. There are many contact points throughout a women's life that could be used to educate about symptoms or encourage a woman to act upon vague symptoms that might lead to referral to a rapid diagnostic centre or diagnostic hub of the future.

> *The barriers to securing a diagnosis, such as symptoms being dismissed or confused with other conditions.*
>
> *Whether women feel they are being listened to by healthcare professionals and their symptoms taken seriously.*

While most women with a gynaecological cancer report a positive NHS experience (Wales Cancer Patient Experience Survey [WCPES] 2021[ii], NHS care rated as 8.5 out of 10, n=388), a concerning number of women (around 6%) rate their NHS care as below average. A single poor experience is one poor experience too many. The WCPES website does not contain the reasons behind those poor experiences, but barriers to diagnosis, and communication with healthcare professionals will very likely feature.

Tenovus Cancer Care wishes to express our concern at the testimonies we have heard from women with gynaecological cancers who have received very poor cancer experiences in the recent past and wish to share those experiences to ensure that no-one must endure the same indignities, pain – both physical and emotional, and stress. We encourage Members to reflect on these testimonies with compassion and reach findings that will help to ensure that women found in similar situations in the future do not experience similar outcomes.

> *HPV vaccination and access to timely screening services including consideration of the inequalities and barriers that exist in uptake among different groups of women and girls.*

Moving forward, the biggest indicator of cervical cancer risk will soon become uptake of the HPV vaccine during the teenage years. Vaccine uptake in children in Wales is

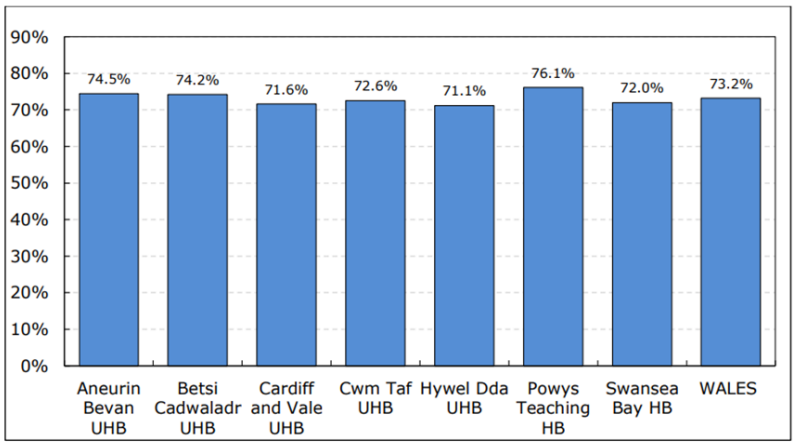
around 79% for first dose, although there appears to be large variation between health boards. The World Health Organisation's (WHO) cervical cancer elimination initiative sets a target of 90% of girls fully vaccinated by 2030[iii].

The Committee might want to ask NHS managers responsible for the HPV vaccine programme why there is variation in uptake of HPV vaccine between health boards. The HPV vaccine is the closest thing we've ever had to a "cure" for cervical cancer and Wales appears to experience a deprivation gap, an increasing inequality that will contribute to avoidable discomfort, suffering and death in the future. The uptake of the second dose is also unreasonably low, why is this the case?

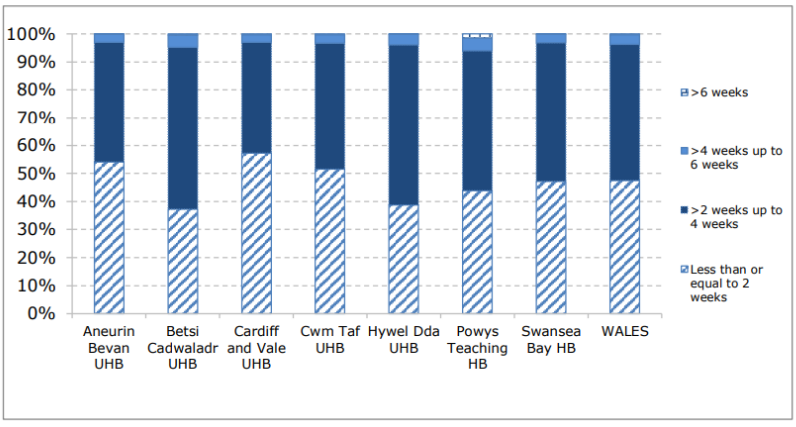
A research paper looking at HPV vaccine uptake in South-West England in 2021[iv] indicated that written consent from parents was a barrier to uptake that could increase the deprivation gap but could be overcome by allowing parents to verbally consent and adolescents to self- consent.

The cervical screening uptake rate in Wales is around 73% according to the most recent annual statistical report (Graph 1b, below). Although deprivation levels were not examined here, there were small amounts of variation in uptake observed between health boards, and the speed of processing and reporting results was variable between health boards (Graph 4, below).

Graph 1b: Combined cervical screening coverage of target age group (individuals aged 25-64) by health board



Graph 4: Time from date sample was taken to issue of result letter, by health board



We understand that there is very little support for victims of sexual abuse to uptake cervical screening in Wales, nothing we are aware of is offered through the invite. Since up to 1 in 4 women will have experienced some kind of sexual assault this seems to be a significant oversight.

> *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.*

Prior to the pandemic cancer services were in a worrying state, with known issues concerning the cancer workforce, waiting times and diagnostic services. The COVID-19 pandemic exacerbated and compounded these existing issues and created new pressures through the suspension of services to prioritise COVID-19 resilience.

We are aware of at least one gynaecological cancer clinic that was cancelled due to the pandemic that has yet to resume, an unacceptable situation. Recovery, if it is to mean anything, must mean the resumption of all oncology activity that was postponed/paused for the 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).*

From the conversations we have had with clinicians we understand that there is no prioritisation of pathways for gynaecological cancers, and that oncologists and other clinicians involved with the treatment and care of these cancers are subject to the pressures and resource constraints of any other cancer. That's not withstanding our understanding that at least one gynaecological cancer clinic has not resumed post-pandemic.

We welcome the development of national optimal pathways for cervical[v], endometrial[vi], ovarian[vii] and vulval[viii] cancers by the gynaecological cancers site group of the Wales Cancer Network, with their aims to standardise care, reduce unwarranted variation and drive improvement and quality.

The comparably poor waiting times for women with gynaecological cancers are extremely concerning. Over the last couple of years around 40% of women have started treatment within the 62-day wait. This has fallen to 25% in December 2022 – during the period this call for evidence has been open. This is extremely disappointing, and strongly suggests systematic pressures that need greater attention and prioritisation across Wales.

> *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.*

There are significant issues regarding the collection and use of cancer data in Wales that impacts what we are capable of understanding as a nation.

For example, reports from the USA indicate that black women are slightly less likely to get gynaecological cancer but 1.3 times more likely to die of it. We do not know if that is the case in Wales because we do not collect ethnicity data through the cancer informatics system. The new system, now available across the NHS, and in use by healthcare professionals, has the technological means of collecting ethnicity data, but we understand that that is a low priority, and unlikely to be acted upon for some time.

Tenovus Cancer Care wants to see that rectified, and the collection of ethnicity data prioritised by the NHS.

> *Whether adequate priority is given to gynaecological cancers in the forthcoming Welsh Government/NHS Wales action plans on women and girls' health and cancer, including details of who is responsible for the leadership and innovation needed to improve cancer survival rates for women.*

Gynaecological cancers are not singled out to any extent within the Cancer Improvement Plan but given the poor waiting times experienced by women with a diagnosis we would expect Health Boards to explain what they are doing to rectify issues within their Integrated Medium-Term Plans (IMTPs). Improvements to cancer waiting times cannot come at the expense of gynaecological cancer waiting times.

The gynaecological cancers site group (the CSG) plays an important role in the development and delivery of gynaecological cancer services. The Wales Cancer Networks describes CSGs as[ix]:

- a single clinical structure providing advice and expertise to the Wales Cancer Network and the Cancer Network Board.
- contributing to policy development and supporting the delivery of the Quality Statement for Cancer. They also provide clinical teams an opportunity to address any site-specific challenges identified at a national level.
- forming the clinical structure of the Wales Cancer Network. They have a diverse membership drawn from the associated multidisciplinary teams that span primary, secondary and tertiary care who care for patients within individual cancer sites across Wales.
- a resource for consultation and advice on clinical guidelines and a support to the national work programme, aiming to enhance patience experience through collaboration, sharing best practice and highlighting areas of service improvement.

It is important to note that clinical input on a CSG is done on a voluntary basis, and with minimal administrative and project support. We believe that the current issues facing gynaecological cancer services warrants additional support for the CSG to enable the identification and co-ordination of activity across and between health boards.

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.

We understand anecdotally that there is “huge unmet need for gynaecological cancer research” in Wales, but since this is not our area of expertise and we defer to other contributors.

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[i] https://collaborative.nhs.wales/networks/wales-cancer-network/clinical-hub/cancer-site-groups/gynaecological-cancer/
[ii] https://wcpes.co.uk/scorecard following application of the Gynaecological cancers filter.
[iii] https://www.who.int/initiatives/cervical-cancer-elimination-initiative
[iv] https://bmjopen.bmj.com/content/11/7/e044980
[v] https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associated-documents/gynae-nop-cervix-pdf/
[vi] https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associated-documents/gynae-nop-endometrial-pdf/
[vii] https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associated-documents/gynae-nop-ovary-pdf/
[viii] https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associated-documents/gynae-nop-vulva-pdf/
[ix] https://collaborative.nhs.wales/networks/wales-cancer-network/clinical-hub/cancer-site-groups/