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 12

Ymateb gan: | Response from: Conffederasiwn GIG Cymru | Welsh NHS Confederation

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Welsh NHS Confederation
Conffederasiwn GIG Cymru

	The Welsh NHS Confederation response to the Health and Social Care Committee's consultation on gynaecological cancer
Contact:	
Date:	20 January 2023

Introduction

1. The Welsh NHS Confederation (WNHSC) welcomes the opportunity to respond to the Health and Social Care Committee's consultation on gynaecological cancers.

2. The WNHSC represents the seven Local Health Boards, three NHS Trusts, Digital Health and Care Wales and Health Education and Improvement Wales (our Members). We also host NHS Wales Employers.

3. Gynaecological cancers represent a various group of diseases with different presentation and management and have a combined incidence second to breast cancer, with incidences predicted to rise in Wales with an aging population.

4. The optimum management involves co-ordinated teamwork between primary and secondary care units and the gynaecological cancer centres who provide the network gynaecological cancer multidisciplinary team (MDT). The local and network level MDT support the implementation of the Single Care Pathway (SCP) that is designed to help improve patients' experience by achieving early diagnosis and reducing waiting times.

Health Inequalities

5. It is important that when considering gynaecological cancer that health inequalities is considered. Health inequalities are the result of many and varied factors and arise as a result of the social and economic inequalities that shape the conditions in which people are born, grow, live, learn, work and age.

6. The Women's Health Implementation Group's discovery report notes that "*inequalities in health outcomes exist between both men and women and between different groups of women in Wales*", recognising these inequities are ultimately preventable and include issues such as cancer screening.

7. It also recognises that women's health and wellbeing is impacted by a broad range of socioeconomic and environmental factors. With that consideration, it is not within the NHS' power alone to address the health inequalities that exist for women. The need for wider action to address health inequalities is the focus of our Health and Wellbeing Alliance briefing, in partnership with the Royal College of Physicians, Mind the gap: what's stopping change?. Any meaningful progress will require coherent and strategic efforts across all sectors and Welsh Government departments. The Alliance has called on the Welsh Government to produce a cross-government plan for reducing poverty and inequalities in adults and children. This should outline the

action being taken across all government departments, setting out how success will be measured and evaluated through shared performance measures and outcomes for all public bodies in Wales, accompanied by guidance on how individual organisations should collaborate to reduce inequalities and tackle the cost-of-living crisis.

Available information and awareness of gynaecological cancers

8. Public awareness of symptoms which could indicate the presence of cancer is crucial to early diagnosis, with evidence that survival rates are associated with the detection and treatment of early-stage disease.

9. Interventions to increase awareness are already undertaken, with Public Health Wales NHS Trust and other national sources used in waiting room areas, to promote HPV vaccination and cervical screening uptake, in line with national campaigns.

10. Understanding GPs' views about this type of activity, however, is crucial prior to implementation. GPs are generally positive about an intervention to improve patients' awareness of gynaecological cancers and ensuring people have accessible information that is relevant to their needs.

Barriers to Diagnosis

11. Members indicate that barriers are wide-ranging, including physical, emotional and practical considerations.

12. Some cancers often present late with non-specific symptoms. These variances include ovarian cancer which tends to present late to vulval tumours which are visible and easier to diagnose if examined.

13. Co-morbidities such as obesity may mask cancer symptoms or present as non-specific symptoms. It is hoped that initiatives such as ‘C the Signs’ will support timely referrals from primary care using ‘red flag’ guidance from secondary care to increase positive diagnoses at an early stage.

14. At times, patients may have intense feelings of embarrassment and a resulting unwillingness, depending on the tumour site. This appears to disproportionately impact women from Black, Asian, Minority Ethnic backgrounds and may in part explain the persistent reticence by the community to seek help. In some studies, even when education levels and health literacy were adjusted for, there were still large differences found for this group.

15. Another barrier in securing a diagnosis is the patients’ mental health status. There is considerable strain for patients with comorbid dementia, learning difficulties or other mental health conditions when presenting with cancer, or a suspect cancer diagnosis. The steps in the diagnostic pathway are usually more complex and require involvement of more specialities, with the involvement of the patient’s support network (family, carers) being essential.

16. Cancer and the side effects of its treatment can have a long-lasting effect on people, meaning that it is vitally important to continue to engage and support patients as they face barriers within their day-to-day lives. We are aware of psychological support that

is offered to patients from specialist clinical psychologists within gynaecological cancers services.

17. Patients must be continuously supported and provided with appropriate information which needs to be tailored to their needs. Any communication problems need to be highlighted by the key worker or clinician in charge of the whole team.

18. Members have also highlighted the importance of community-based third sector organisations, which can offer emotional and practical support. Charities provide an invaluable service to their communities, at times providing transport for many of patients to attend clinic appointments and chemotherapy and radiotherapy sessions.

19. One health board identified the high volume of urgent suspected cancer (USC) referrals as an indication that women are being listened to in primary care. Within secondary care, PREMs and PROMS for the Post-Menopausal Bleeding pathway have led to careful patient selection for hysteroscopy, with a patient centred approach reducing anxiety and allowing for a successful diagnostic procedure.

HPV vaccination and access to timely screening services

20. The screening division inequities 2020-21 report by Public Health Wales showed the inequity gap, representing the difference between cervical screening coverage in the least deprived communities compared to the most deprived communities, was 12.1 per cent and this trend was evident across all health board areas in Wales. The report said the screening inequity gap in coverage between the most deprived and the least deprived areas was largest in Aneurin Bevan University Health Board (UHB) at 12.9 per cent and lowest in Hywel Dda UHB at 8.7 per cent.

21. The report also indicated that coverage of cervical screening is lowest in the youngest age group (25-29 years) eligible for screening. Coverage of eligible participants aged 25-29 was 63.4 per cent compared to 77.2 per cent in participants aged 50-54.

22. In relation to the HPV vaccine, this is delivered in two doses, but will be reduced to one dose from 2023 for 13-year-olds. Figures provided by one health board for August 2022 indicate a low up-take for the first dose for 13-year-olds at 57 per cent. This increased in 14-year-olds, with a final uptake of 78 per cent.

23. It was suggested that low return rates of consent forms have been a contributory factor for the low uptake of the vaccine. This may also be a post COVID effect, as other vaccinations have also achieved lower uptake rates. Social media is used locally to give notice of vaccination programmes at schools and as a reminder to sign consent forms.

NHS recovery of screening and diagnostic services

24. The Covid-19 pandemic has had a serious impact on services and resulted in significant waiting time increases for patients, with health boards experiencing reduced theatre capacity. Members have indicated that the number of lists for gynaecology have yet to return to pre-pandemic levels and prioritisation of patients for theatre is based on clinical urgency, with USC and confirmed cancer cases taking priority, followed by urgent and then routine cases.

25. In relation to diagnostics, one member informed us that 80 per cent requiring a diagnostic radiology investigation on the SCP receive it within 14 days. When diagnostic biopsy is carried out, pathology processing can be up to 4 weeks. They also said a change to guidance for the ovarian cancer pathway is proposed for suspected ovarian cancer patients for CT imaging rather than MRI due to the overlapping symptoms with GI cancers.

26. Other actions which have been drawn to our attention include dedicated USC slots in most outpatient general gynae clinics to allow access to first outpatient appointment within ten days when possible. Also, additional outpatient and diagnostic clinics have been created to facilitate post-pandemic recovery.

27. On screening, Public Health Wales Screening Division oversees cervical screening in Wales and is the accountable body in terms of promoting uptake, timely screening services recovery, and reducing inequity. Support from Sexual and Reproductive Health for cervical screening was done post pandemic as a catch-up recovery programme to support primary care in the last financial year.

Prioritisation of pathways as part of NHS recovery

28. Cancer pathways take priority over non-cancer work and women are more likely to face long waits with benign conditions, including conditions such as severe dysfunctional uterine bleeding, stage 3 and 4 endometriosis and prolapse and continence issues.

29. Cancer pathways for all conditions face the same constraints in a system that is under pressure in other areas. One health board indicated that gynae cancer modelling has changed the number of initial assessments offered to fit demand with 115 USC appointments per week (from 82) but this is still short of the required 125 per week. Others noted the use of dedicated suspected cancer slots available in more general gynaecology outpatient clinics to ensure patients can be offered a first appointment within ten days.

30. One of our members stated that, as of November 2022, gynaecology had a compliance rate of 42.1 per cent with the SCP. The compliance rate has been improving over the previous year, however, the backlog of patients has meant a focus on treating the longest waiting patients, impacting on the 62 day treatment rate. The number of patients waiting over 104 days and over 62 days have steadily reduced over the past year, and it is expected therefore that the SCP compliance will continue to improve.

Local disparities in gynaecological cancer backlogs

31. As part of the SCP, a patient with suspicion of cancer should be seen in secondary care 10 days from the point of suspicion. However, as a result of the post-pandemic backlog, members are reporting delays in patients accessing diagnostic services and are taking measures to reduce the backlog and improve the timeliness of the pathway at each stage, including rapid access to initial diagnostics.

32. However, one member noted that it is not possible to deliver all pathways in all areas of a health board due to presence of expert clinicians, equipment required and dedicated space.

Disaggregated Data by cancer type

33. Members did recognise the importance of disaggregated data, suggesting that data should be reviewed and disaggregated nationally to provide meaningful information, particularly due to the low numbers for some cancers.

34. However, local audits taken at sites in one health board area in relation to the deprivation index demonstrate a clear correlation between deprivation and late presentation for patients with a gynaecological cancer.

Leadership and Innovation in forthcoming action plans

35. Gynaecological cancer leadership and innovation, whilst not a direct element in the action plan, has received significant attention through the efforts of groups and individuals across the Welsh health and life science ecosystem. Work has taken place across the Wales Cancer Research Centre and the NHS Wales precision medicine initiatives, with innovation driving towards better and novel therapeutics and new approaches to earlier and more specific diagnosis.

36. All Wales Medicines Strategy Group (AWMSG) is leading on the implementing genome sequencing panels for ovarian cancer patients in line with UK requirements. The regional pathology centres will include gynaecological cancer remits.

Research and Innovation

37. The need for further research was recognised in the implementation group's discovery report which listed gynaecological cancer as an area requiring more research evidence.

38. As this is a recognised area requiring further research, members did indicate several areas which could be expanded and improved:

    - Adoption of NICE approved novel interventions.
    - Opportunities to participate in gynaecological oncology trials. These require research time for clinical leads to be agreed, for clinical and pharmacy infrastructure and expertise to be in place, and for conduits to sponsors, CRO or direct to pharmaceutical companies, to be highly visible.
    - Health Care Research Wales discussions to strengthen investment into gynaecological cancer, including through sponsorship of clinical academics.
    - Wales level planning to respond to major funder calls and also general and gynaecological charities.

39. There is also good evidence from clinical trials that patients treated within a trial setting fare better than those treated outside of a trial setting, and this is thought to be due in large measure to the benefits of treatment according to documented protocols. Standardisation of protocols across the Cancer Network will enable outcome assessment to be performed in a uniform manner, and staff gain greater expertise by concentrating on a lesser number of well-defined protocols.

40. There is also a need to expand capacity to enable additional research, including large scale data analysis through SAIL, and linked genomic resources. Attention should also be given to pre-malignant conditions where patients are at higher risk of developing a gynaecological cancer, most specifically endometriosis.

Conclusion

41. Inequalities affect the experience and outcomes for women in Wales who are suspected or diagnosed with a gynaecological cancer. This is not purely along gender lines, with different groups of women experiencing different barriers to diagnosis and treatment.

42. Whilst the NHS is taking action to raise awareness and support patients, it cannot address the number of underlying factors which ultimately contribute to this inequity and a cross-sector approach is required to address the obstacles women face in gaining access to services.

43. Prevention and early intervention are also crucial to reduce the exposure to risk factors which could be brought about due to socioeconomic conditions, and also address the barriers to screening and diagnosis, which is vital due to link between early diagnosis and survival rates.