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Llywodraeth Cymru  
Welsh Government

Russell George MS  
Chair,  
Health and Social Care Committee

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19 February 2024

Dear Russell

Thank you for your letter of 6 December 2023 on behalf of the Health and Social Care Committee regarding its inquiry into gynaecological cancer and enclosing the report: *Unheard: Women's journey through gynaecological cancer*.

I am grateful to the Committee for its work in investigating the care and experience of women diagnosed with a gynaecological cancer and I apologise for the slight delay in responding.

I was grateful for the opportunity to have given evidence to the Committee on this important issue and to receive your final report. I have given careful consideration to the recommendations made and attach below my detailed response.

Yours sincerely

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

## Written Response to the Health and Social Care Committee's December 2023 Inquiry Report on Gynaecological Cancer: "Unheard: Women's journey through gynaecological cancer"

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The Welsh Government welcomes this report from the Committee as we recognise the importance of women presenting to the NHS with concerns about gynaecological cancer being heard. It is important that NHS services are responsive to women's concerns and that people are referred appropriately for rapid investigation of their symptoms. As those giving evidence to the Committee confirmed this is not always the case and more needs to be done to address these problems.

In doing so it is also important that we recognise that the vast majority of those receiving cancer care for gynaecological cancer consistently report high levels of patient satisfaction with NHS services. This can be seen in all three national cancer patient experience surveys conducted over the past decade. Despite this, it is important the Welsh Government from a policy perspective, and the NHS from a service delivery perspective, considers what more needs to be done to ensure all patients receive high quality care right from the beginning of their patient journey.

The Welsh Government is committed to improving cancer services and outcomes. Cancer has consistently been a high priority for the Government and NHS in Wales, as reflected by the series of national strategies, plans and policies introduced since 2006. The Welsh Government's current policy approach is set out in the 2021 Quality Statement for Cancer and its intention is to guide health board and trust planning of cancer services in line with a series of nationally agreed clinical pathways and for the NHS Executive use data to regularly oversee the consistency of service delivery.

We understand that cancer performance for gynaecological cancer must improve and aspects of this policy, and the NHS Cancer Improvement Plan, will support improvement in the experience of care for women with gynaecological cancers. Often these efforts are intended to benefit multiple cancers, such as Rapid Diagnostic Centres and educational support for GPs. Some actions are more specific to gynaecological cancer, such as the programme for cancer waiting time recovery being introduced by the NHS Executive, which focuses on three cancer types, including gynaecological, in recognition of the recent waiting time performance.

All this work is being done to the backdrop of the NHS experiencing severe financial challenges, long-term increases in demand for cancer and non-cancer care, while having to recover from the significant impact of the pandemic; not least in terms of longer waiting lists. The national planning framework issued to the NHS requires strict prioritisation of service development within the financial means available to the NHS.

In response to the specific recommendations made:

**Recommendation 1: The Welsh Government should work with the relevant health professional bodies and health boards to promote gender sensitivity and cultural competence among healthcare professionals. This 'relationship-based care' model should include ensuring there is adequate [sic] time for appointments to thoroughly address patients' concerns, and encouraging empathetic communication between patients and healthcare professionals, acknowledging the unique health needs and experiences of women.**

Response: Accept

This will be a key focus of the NHS Women's Health Plan. The Discovery report, published in December 2022 set out six priority improvement opportunity areas including the need to identify and embed techniques and behaviours that ensure women's and girl's voices are heard in every interaction they have with the NHS.

Financial Implications: none, included in the funding for the Strategic Clinical Networks.

**Recommendation 2: The Women's Health Plan for Wales should be completed and published before the end of the year, and the Welsh Government should support NHS Wales in doing this. The plan should include a specific focus on the gynaecological cancers, helping to improve women's health inequalities by raising awareness around the issues, improving access to health care and improving cancer outcomes for women diagnosed with a gynaecological cancer.**

Response: Accept in part

The Women's Health Plan will be published by the end of the calendar year. The Plan will help to improve women's health inequalities by raising awareness around the issues relating to women's health and improving access to care. However, the Welsh Government's policy intentions and actions specifically related to gynaecological cancer are already set out for the NHS in the Quality Statement for Cancer and the NHS response was described in the Cancer Improvement Plan.

Financial Implications: none, included in the funding for the Strategic Clinical Networks.

**Recommendation 3: In its response to this report, the Welsh Government should provide details of:**

- **the associated research budget to support the women's health plan, and**
- **what the research priorities will be, including whether there will be specific funding for gynaecological cancer research.**

Response: Accept in principle

The Discovery Report highlighted the need for qualitative and mixed methods research on key topics that support the needs of women and girls. Areas requiring more research evidence were also highlighted. The Women's Health Network will further refine the research needs relating to the development of the Women's Health Plan. Work is underway to develop options to ensure resources are prioritised for research on women's health over the next few years. These options will not include specific funding for gynaecological cancer research because the Welsh Government has already agreed and funded a national approach to cancer research as part of the Cancer Research Strategy for Wales.

Financial Implications: These will be developed as part of the identification of options.

**Recommendation 4: The Welsh Government should work with health boards to ensure that an assessment is made of gynaecological cancer-related services lost during the Covid-19 pandemic, and ensure those services are reinstated as a matter of urgency. In its response to this report, the Welsh Government should:**

- **report back on the timings for re-instating those services and,**
- **where services are not being reinstated, provide an explanation for this.**

Response: Reject

The policy intention is to transform how pathways and clinics are arranged and delivered to meet the cancer waiting time target for people with gynaecological cancers. The number of people referred onto the suspected cancer pathway for gynaecological cancer has seen year-on-year increases since 2020. By 2023, the average number of people referred for suspected gynaecological cancer per month was 50% higher than in 2020. This along with the increasing complexity of service delivery, and the limited capacity that can be deployed through existing service models means we do not wish to see the pre-pandemic clinical service model reintroduced. The intention behind the NHS Executive's introduction of the national optimal pathways, supported by the cancer waiting time recovery programme, is to change how pathways and the service model involved are delivered.

Financial Implications: none, the recommendation is rejected.

**Recommendation 5: The Welsh Government should provide a set of clear and measurable objectives and targets for the NHS Executive in relation to improving gynaecological cancer outcomes, setting out how they are aligned to the work of the Wales Cancer Network and the Cancer Improvement Plan priorities. It should do this at the time of responding to this report.**

Response: Accept

Improvement in cancer outcomes will result from a range of factors, including population factors and access to NHS cancer care. The NHS Executive does not have the responsibility or the ability to improve cancer outcomes itself. However, the NHS Executive will support the NHS to improve outcomes through the local planning and delivery of their services. It will set out how services should be planned and delivered in national pathways of care. It will collate, review, and use data on care provision to support the Welsh Government to hold the NHS to account for improving cancer services. It will also lead a national programme for cancer waiting time recovery with health boards and trusts for those cancers with the most challenged waiting time performance. This will include transforming clinical services and pathways to improve waiting times for gynaecological and all cancers. The programme milestones are still in development, and I will write in follow up to the Committee when they are agreed.

Financial Implications: none, the funded programme will accommodate the development of milestones.

**Recommendation 6: The Welsh Government should set out how it intends to support health boards to maximise the benefits of regional working, specifically to overcome the barriers facing services due to the incompatibility of ICT systems. It should do this at the time of responding to this report.**

Response: Accept

Cancer services are already heavily regionalised, including for gynaecological cancer treatment and multi-disciplinary management. It is the initial outpatient management and investigations that tend to be locally delivered, as well as non-specialist palliative care and any post-treatment support. Regional MDTs coordinate the interaction of different clinical teams, and the patient is supported by a nominated key worker to coordinate their care. To help integrate care between organisations and clinical teams the Welsh Government has invested around £12 million to introduce a new cancer information solution for Wales. This introduces a series of new clinical record types that can be viewed by any clinician with access to the Welsh Clinical Portal. The new standardised digital records available for use across clinical settings include an oncology outpatient note, an oncology inpatient note, a

radiotherapy treatment summary, a systemic anti-cancer treatment summary, as well as a multi-disciplinary meeting record. The patient's diagnostic procedures and reports are already available through the Welsh Clinical Portal alongside these new records. The funding also provided for the southeast Wales Cancer Centre to move from a siloed digital system for organising patient care (CaNISC) onto the integrated Wales patient administration system (WPAS). This has been integrated with Cardiff and Vale University Health Board's unique patient management system. The development of this new functionality allows Wales to provide better data to the national clinical audit of ovarian cancer. We are giving further consideration to additional investment in the cancer informatics solution to finalise, improve and integrate the cancer clinical record with additional national clinical systems.

Financial Implications: The digital investment case under consideration is costed at £2.6 million during 2024-25.

**Recommendation 7: The Welsh Government should undertake an evaluation of the Rapid Diagnostic Centres (RDCs) to optimise their performance and ensure that they contribute effectively to early cancer detection. This should include ensuring that patients get equal access to RDCs across different parts of Wales, in particular underserved areas. It should report back to us with the findings of the evaluation within 18 months of publication of this report.**

Response: Accept

The NHS Executive's Wales Cancer Network is undertaking an evaluation of the Rapid Diagnostic Centres, and the report will be forwarded to the Committee when available.

Financial Implications: none, within existing programme resources.

**Recommendation 8: The Welsh Government should:**

- **work with NHS Wales to achieve the WHO's target of 90 per cent uptake of the HPV vaccine; and**
- **by the end of this Senedd, report on the progress made in relation to meeting the WHO's 2030 vaccination, screening and treatment targets for cervical cancer. And as part of this include data on the incidence of cervical cancer amongst women in Wales and how this has changed during the course of this Senedd.**

Response: Accept in part

For HPV vaccination in Wales there is already an uptake target of 90% which is applicable for both boys and girls. This uptake target was communicated to the NHS in Wales recently via Welsh Health Circular WHC/2023/16. Health boards should achieve 90% uptake by the time individuals reach 15 years of age. This uptake standard is also reflected in the NHS Wales performance framework and HPV vaccination uptake is reported quarterly by Public Health Wales. Similarly, there is already an 80% coverage standard for cervical screening. Around 70% take up the offer when invited and Public Health Wales is working to improve uptake. The target for cervical cancer treatment is set in the Quality Statement for Cancer, which states that at least 75% of people should start first definitive treatment within 62 days of their point of suspicion. The Welsh Government is routinely working with health boards to achieve these targets and incidence of cervical cancer is already reported annually by Public Health Wales. I am happy to provide a written statement on progress at the end of the Senedd term.

Financial Implications: The cost of achieving these targets cannot be quantified.

**Recommendation 9: The Welsh Government should work with Public Health Wales to review its equity strategy to:**

- **ensure everyone eligible for cervical screening has the opportunity to take up their offer; and**
- **take more targeted action to specifically address those groups of women where take-up of screening is known to be low.**

Response: Accept

The Welsh Government recognises the need to improve uptake of cervical screening by identifying the enablers and barriers to access. Public Health Wales has recently established a group which will focus on uptake and equity within the screening programme.

Financial Implications: none, within existing resources.

**Recommendation 10: The Welsh Government should, in its response to this report, outline what work is being undertaken to ensure that NHS Wales is set up to implement self-sampling at pace, if approved. This should include details of any redirection of resources that might be necessary.**

Response: Accept

Cervical Screening Wales is working with the other UK screening programmes in order to undertake an in-service evaluation of self-sampling within cervical screening. This will enable the programme to understand and evaluate self-sampling within the context of a population-based screening programme. As part of the evaluation, pathways will be developed to offer safe and effective self-sampling. Self-sampling will only be implemented if it is recommended by the UK National Screening Committee and the in-service evaluation will help inform the Committee's recommendation.

Financial Implications: none, the in-service evaluation will help inform what resources are required to implement self-sampling should it be recommended.

**Recommendation 11: The Welsh Government should, in its response to this report, advise how it is working with Public Health Wales to ensure the information provided at cervical screening appointments makes clear that such screening does not test or screen for other gynaecological cancers, and includes information about the symptoms of other gynaecological cancers. This information should also be provided when women attend their breast screening appointment.**

Response: Accept

Public Health Wales will amend the patient information for cervical screening to clarify it does not test for other types of gynaecological cancer. The public information already includes reference to symptoms of cervical cancer and the need to seek advice from the GP if a person has those symptoms. When women present for their breast or cervical screening appointments, the 'every contact counts' approach will be developed with PHW to ensure that evidence-based behavioural interventions are used to promote women's understanding that cervical screening does not test for other types of gynaecological cancers. This will include consideration of the effective provision of broader information and contact details on

where to go for support on women's health issues, including menopause and pelvic floor clinics, already in place in some health boards. Public Health Wales will advise on what information should be delivered to provide the greatest benefit and reduce inequalities.

Financial Implications: none, within existing resources.

**Recommendation 12: The Welsh Government should work with Public Health Wales, and community leaders and organisations to develop and implement a series of campaigns to raise awareness about the symptoms of gynaecological cancer. These campaigns should:**

- **be re-run frequently, and should encourage women to seek medical attention promptly if they experience any symptoms;**
- **include clear messaging to better engage the public in the promotion of healthier lifestyle choices and the personal benefits associated with these choices;**
- **include consideration of cultural, linguistic and socio-economic factors and be targeted at specific populations and communities that are disproportionately affected by health inequalities.**

Response: Accept in part

The Welsh Government already routinely works with third sector partners and NHS organisations to amplify cancer awareness campaigns. The Welsh Government will look to partner with cancer charities to periodically amplify their symptom awareness information for gynaecological cancer. This information will also be promoted by Public Health Wales and health boards. The Welsh Government already works with local organisations to promote the benefits of healthier lifestyle choices and this work already considers the need to address health inequalities. If and when finances allow, campaigns will be carefully targeted which has been proved to be more effective than broad public awareness campaigns.

Financial Implications: within existing resources.

**Recommendation 13. In its response to this report, the Welsh Government should provide details of any plans it has to evaluate the decision support tool, 'Gateway C', to see what impact it is having on GP referral rates.**

Response: Accept

GatewayC is a healthcare professional education resource rather than a decision support tool. Health Education and Improvement Wales rolled out GatewayC to primary care in Wales and is undertaking a review of the resource's implementation.

Financial Implications: none, is included within existing resources.

**Recommendation 14. The Welsh Government should work with the relevant professional bodies and NHS Wales to:**

- **ensure continuing medical education opportunities have an appropriate focus on gynaecological cancers. This should include a conference/webinar to update GPs on the latest guidelines and diagnostic techniques focused on gynaecological cancers to take place by the end of March 2024;**
- **ensure the clinical guidelines that outline the symptoms and risk factors associated with gynaecological cancers are clear and being implemented. This should include an audit of GP referrals and patient outcomes related to gynaecological cancers to provide feedback to GPs to help them improve their diagnostic skills;**

- **provide GPs with support from secondary care to assist them in the assessment and referral of patients with potential gynaecological cancer symptoms. For example, telemedicine solutions that allow GPs to consult with specialists remotely (this can be particularly useful for GPs in rural or underserved areas).**

Response: Accept in part

All GPs in Wales have been provided with desktop access to GatewayC to support their continuing professional development with regard to the identification of possible symptoms of cancer, including gynaecological cancer symptoms. Clear and well understood national guidelines are in place for the symptomatic and risk-based assessment of people presenting with possible symptoms of cancer. The NHS Executive already tracks suspected cancer referral rates and numbers referred at main cancer type level (i.e. gynaecological cancer) and how this varies between NHS organisations. There are approximately half the number of gynaecological cancer diagnoses per year as there are GPs in Wales, nevertheless, GPs are referring around twenty times the number of diagnosed cases for investigation of symptoms of gynaecological cancer. The conversion rate on the gynaecological cancer pathway overall is only 5%, and for some specific outpatient types, as low as 1%. This shows General Practice in Wales is taking women's concerns about gynaecological cancer seriously and applying very low thresholds of suspicion to refer women. In addition, new functionality in the national digital system used to make electronic referrals into secondary care allows for secondary care clinicians to provide advice or ask for further information relating to a patient referral.

Financial Implications: none.

**Recommendation 15. The Welsh Government, in conjunction with the Wales Cancer Network, should commission an urgent review of the incidence, trends and high-risk populations in relation to emergency presentations with a gynaecological cancer, broken down by each of the gynaecological cancers. This review should include access to primary care, symptom recognition amongst GPs, misdiagnosis and communication and referral processes. The findings should be shared with the Committee within six months of the publication of this report.**

Response: Reject

We are aware emergency presentation of cancer often leads to inferior outcomes for patients. Understanding the cause of these and attempting to resolve them, is part of the work of NHS Executive's cancer network. The NHS Executive, working with Digital Health and Care Wales has added source of suspicion data, so that the cancer network can look at trends in presentation from sources such as emergency departments. This is also likely to be covered in the forthcoming ovarian cancer audit. However, there is insufficient resource available to undertake a formal review of this matter within the timeframe requested.

Financial Implications: none, the recommendation is rejected.

**Recommendation 16. The Welsh Government should clearly outline its ongoing commitment to prioritising gynaecological cancer and to providing the essential attention and resources required to positively impact women's health. To ensure continual improvement in gynaecological cancer care, the Welsh Government should work with the NHS Executive to consistently publish key performance data for the cancer interventions (such as waiting times, patient outcomes, and access to care), promoting transparency and better women's health outcomes.**



Response: Accept

Cancer is one of the designated six priorities in the NHS planning framework and the NHS Executive is delivering a waiting time recovery intervention that includes three specific cancer types, including gynaecological. This reflects the ministerial prioritisation of three main cancer types for national action at a national cancer summit in March 2023 and will be supported by £2 million of national funding per year for three years. The NHS Executive's cancer network includes a specialist advisory group for gynaecological cancers, that brings experts from across Wales together to collaborate on service improvement. It led the development of national pathways for three of the five main sub types of gynaecological cancer. The national clinical audit and outcomes review programme has also been expanded to include a clinical audit of ovarian cancer care, reflecting the need to support improvement in outcomes. Digital Health and Care Wales already publishes waiting time data for gynaecological cancer and Public Health Wales already publishes outcome data for gynaecological cancers.

Financial Implications: none, gynaecological cancer has already been prioritised.

**Recommendation 17. The Welsh Government should work with the All Wales Medicines Strategy Group and relevant professional bodies to:**

- **improve understanding of the challenges of implementing new NICE recommended drugs to help alleviate some of the frustrations and misunderstanding there is among healthcare professionals;**
- **address some of the challenges facing health boards in implementing new NICE-recommended drugs, setting out a plan for how they will ensure there will be sufficient capacity to allow women in Wales, diagnosed with a gynaecological cancer, to benefit from prompt access to these new treatments. This should include an analysis which new cancer drugs for treating gynaecological cancer are likely to be approved in the short to medium term.**

Response: Accept in principle

Officials have undertaken a comparison of the availability of medicines for gynaecological cancers between England and Wales which confirms all medicines approved by the National Institute for Health and Care Excellence (NICE) are available equitably in Wales and England. This includes any medicines approved for use in the Cancer Drugs Fund (CDF) since NICE took responsibility for managing access to the CDF in July 2016. Although we acknowledge that prior to 2016 there may have been greater variability of access and off-label use of bevacizumab was only made available routinely in Wales in 2019, in general, medicines for gynaecological cancer are made available in Wales at least as promptly as they are in England. New Treatment Fund data suggest they are made routinely available within 30 days of their recommendation by NICE. This view is supported by the evidence given by Target Ovarian Cancer.

In order to support understanding we will write to health boards and trusts drawing attention to the resources the All-Wales Therapeutics and Toxicology Centre (AWTTC) has produced describing the different routes to making medicines available in Wales. We are aware that a number of new cancer drugs that require genetic test prior to initiating treatment are creating capacity challenges for health boards, and this affects at least one new treatment for ovarian cancer. In the future many more medicines will require companion genetic tests to be undertaken prior to initiating treatment. Health board and trust chief executives are working together to better plan for the introduction of these new treatments, using the NHS Executive's clinical networks and experts to identify the implications across the pathway of implementing new drug therapies that require genetic testing and sample preparation. To

support this planning work, AWTTTC has recently agreed and is trialling a revised horizon scanning process. This builds on AWTTTC's role as a partner in the Medicines and Healthcare product Regulatory Agency's (MHRA's) Innovative Licensing and Access Pathway (ILAP) for new medicines and the process agreed with the All-Wales Genomics Oncology Group in 2022.

Financial Implications: none, within current resources and planned activity.

**Recommendation 18. The Welsh Government should write to all health boards to remind them of their duty to ensure that all patients are treated with dignity and respect.**

Response: Accept

I will circulate the Committee's report to health boards and in doing so provide such a reminder in the context of the patient stories you have documented.

Financial Implications: none.

**Recommendation 19. The Welsh Government should, within 6 months, undertake a comprehensive review of the gynaecological cancer workforce in Wales, identify where there are, or are likely to be, shortages, and take steps to recruit into those posts. It should report its findings to us on completion of the review.**

Response: Accept

Defining the gynaecological cancer workforce is open to interpretation but should include oncologists, gynaecologists, and specialist nurses with a specialisation in gynaecological cancer. There are many other healthcare professionals that contribute to the pathway, in particular histopathologists and radiologists. Health Education and Improvement Wales (HEIW) has initiated a two-year project to review the cancer specialist nursing workforce across Wales and this will include specialist nursing for gynaecological cancers. This work is identified as a priority in HEIW's 2024-25 Integrated Medium-Term Plan and will involve working with the NHS Executive's cancer network and Macmillan Cancer Care. HEIW is also developing strategic workforce plans in a number of areas as set out in the National Workforce Implementation Plan (NWIP). As part of its broader work programme and linked to the annual Education and Training Planning cycle, HEIW reviews workforce issues and provides advice to Welsh Government on the need to increase places in the education and training pipeline. In light of the recommendation, HEIW will consider a specific focus on the specialist gynaecological cancer workforce including oncologists, gynaecologists and specialist nurses who specialise in gynaecological cancer as part of this work.

Financial Implications: it is not possible to quantify this at this stage.

**Recommendation 20. The Welsh Government should instruct Health Education and Improvement Wales to include gynaecological cancers in its work on pathway workforce planning methodology.**

Response: Accept

Health Education and Improvement Wales has included gynaecological cancer in its pathway workforce planning methodology.

Financial Implications: none, within planned resources.

**Recommendation 21. In its response to this report, the Welsh Government should set out what data on gynaecological cancer performance it intends to publish and by when. The publication of this cancer management data is essential for accountability, transparency, informed decision-making, and ultimately, improving the quality of cancer care and outcomes in Wales.**

Response: Accept

Digital Health and Care Wales has published 38 data items of cancer performance, 16 of which include specific data for gynaecological cancer. The NHS Executive is working to enhance NHS management data, specifically to include cancer sub-types for closed pathways. This would provide information on which types of gynaecological cancer had been treated within the target. This is likely to be added to the DHCW dashboard when ready later this year. In addition, the NHS Executive is looking to develop route to diagnosis and diagnostic performance data as part of health board business intelligence tools. It is possible some of this data will not be validated for accuracy and therefore it may only be used internally by the NHS as management data.

Financial Implications: none, within planned resources.

**Recommendation 22. In its response to this report, the Welsh Government should set out what oversight it has of the cancer informatics system (CIS), and how it will ensure that the system is fit for purpose and will provide value for money. The response should include details of how the CIS is supporting a key objective in the Cancer Improvement Plan around the digitalisation of cancer pathways.**

Response: Accept

Please refer to my response to recommendation six with regard to the impact of the new digital system. The Welsh Government has funded the cancer informatics solution via the Digital Priorities Investment Fund and has therefore grant managed the programme. The Programme has been subjected to Gateway review and further development will be subject to an external review of the programme. Direct oversight of delivery is through the Cancer Informatics Programme Board and its Senior Responsible Officer.

Financial Implications: The digital investment case under consideration, which includes an external review, is costed at £2.6 million during 2024-25.

**Recommendation 23. The Welsh Government needs to take action, together with the Wales Cancer Research Centre, and with advice from the Wales Cancer Alliance, to develop Wales' medical research environment so that it can compete with other parts of the UK for research funding. This should include consideration of whether a centre of research excellence could be established specifically for gynaecological cancer research. We note this will require the political will and the redirection of some research funding.**

Response: Accept

It is vital that Wales has a strong cancer research environment that can contribute high-quality research to tackle this global endeavour. Over the years, cancer has been the single biggest area of Welsh Government health research investment. Significant government funding has, for example built key cancer research infrastructure such, as the Wales Cancer Research Centre, the Wales Centre for Primary and Emergency (including Unscheduled) Care Research (PRIME), and the Centre for Trials Research (CTR).

The crucial importance and mutual benefits of partnership working in cancer research is recognised, which is why Health and Care Research Wales look to collaborate widely in cross-funder schemes and partnerships that open funding opportunities for Welsh research of a scale we cannot offer within our own budgets. For example, we co-fund the Cardiff Experimental Cancer Medicine Centre (ECMC) with Cancer Research UK (CRUK) and the other UK government health and care R&D divisions which enables patient access to early-stage clinical trials and translation of scientific discoveries into new cancer treatments.

Ministers have given clear instructions to officials on the need to prioritise resources onto women's health research over the next few years and officials are currently working up proposals on how best to do this.

With the support of Health and Care Research Wales, the Welsh research and wider stakeholder community has worked collaboratively to develop a Cancer Research Strategy for Wales (CReSt) that sets a way forward for cancer research in Wales which, in turn, will help address the significant burden of cancer within the population of Wales. Published in July 2022, CReSt provides a strategic platform for co-ordinating cancer research in Wales, identifying six priority research themes where there is a strong track record of research excellence and future opportunity (Precision & mechanistic oncology; Immuno-oncology; Radiotherapy; Cancer clinical trials; Palliative & supportive oncology; Population health-based cancer prevention, early diagnosis, primary care and health services research).

The Wales Cancer Research Centre (WCRC) is providing strategic oversight and coordination for the implementation of CReSt and I have provided up to £1m of additional funding to support the Centre with this work up until 2025. There is gynaecological cancer research activity already happening in Wales across a number of the CReSt themes (e.g. a Health and Care Research Wales PhD Studentship investigating the value of repurposing drugs to treat chronic therapy-resistant ovarian cancer; a Welsh Government and Industry backed SMART Expertise project to advance a group of novel epigenetic drugs and ADCs to tackle ovarian cancer).

We will consider the opportunity for Welsh researchers to build on these emerging strengths to generate additional resources and infrastructure on gynaecological cancers, as well as the potential for a focus in emerging work to bring the NHS, industry, and third sector together to collaborate on cancer innovation.

Financial Implications: none, within planned resources.

**Recommendation 24. In its response to this report, the Welsh Government should set out:**

- **how many clinical trials are currently open for women with a gynaecological cancer in Wales;**
- **how they will work with health boards to reverse the decline in clinical trials open for women with a gynaecological cancer; and**
- **how clinicians can be better remunerated for this work**

Response: Accept

There are 13 gynaecological cancer studies currently open across various NHS sites including north Wales, southwest and southeast Wales. Two are commercial studies and 11 are non-commercial. The Welsh Government, via Health and Care Research Wales, is working with health boards and trusts on increasing studies across all disease areas and the CReSt strategy is providing a focus on increasing cancer trials. An important part of this

work is ensuring that NHS organisations have a strong research culture. Welsh Government has published a new Research and Development Framework to better embed and integrate research into all aspects of health and care services in NHS Wales. It is being published as consistent national guidance to all NHS organisations and is used for monitoring performance.

The Framework outlines Welsh Government's expectations, which includes having workforce plans in place to ensure that NHS staff have the opportunity to support research, by including research in all NHS job descriptions and giving protected time for research for NHS staff through job planning and Performance and Development Reviews. NHS organisations are also expected to enhance research delivery capacity amongst the workforce, including the capability to support clinical trials, ensuring good clinical governance and best practice. In addition, NHS organisations should generate research income for non-commercial studies (i.e. from research funders, research councils and third sector organisations) and commercial studies (i.e. from industry partners) to facilitate capacity building. There are particular benefits for undertaking commercial studies where an element of the income provided to the NHS organisation can be used to support respective clinicians undertaking the studies and for capacity building within their departments.

Financial Implications: none, with planned resources

**Recommendation 25. The Welsh Government should work with health boards and relevant stakeholders to ensure the benefits of palliative care are promoted to patients, general practitioners and clinicians in acute hospital settings to address the misconception that palliative care is only for the very end of life.**

Response: Accept

The NHS Executive's National Palliative and End of Life Care Programme Board has responsibility for driving change and overseeing health board efforts to deliver the Welsh Government's vision for improving end of life care in Wales. This recommendation to promote the benefits of palliative care to all stakeholders will be addressed in the Board's work programme and advisory groups. These groups include Paediatric Specialist Palliative Care, Adult Specialist Palliative Care, Policy and Third Sector, Children and Young People, as well as Professional Advisory groups.

Financial Implications: none, included within existing resources.

**Recommendation 26: In its response to this report, the Welsh Government should provide an update on the progress it has made in implementing the quality statement for palliative and end of life care, and specifically how it is ensuring access to palliative care is underpinned by equity.**

Response: Accept

Since the publication of the Palliative and End of Life Care Quality Statement in October 2022, the NHS Executive's National Palliative and End of Life Care Programme Board has been established and is working to advise on its implementation. The Programme Board has delivered on two phases of the End-of-Life Care Funding Review, providing recommendations that align with the aims of the Quality Statement. The main focus of the Programme Board team over the past 12 months has been on the third and final phase of the palliative and end of life care funding review and interim recommendations are due to be completed by the end of January 2024. These recommendations will also align with the actions set out in the Quality Statement.

All workstreams of the programme are underpinned by equity and diversity and the Programme Board works through the NHS Executive to help equip palliative and end of life care providers to ensure person centred value-based care is available for all those who need it. The programme team is committed to developing active measures to identify and reduce those evidenced inequities including diagnosis, mental health, dementia, age, geography, ethnicity, sexual and gender identity, and poverty. The work of each subgroup of the Programme Board is also focused on delivery of different aspects of the Quality Statement.

Financial Implications: none, included within programme resources.