Agenda - Health and Social Care Committee

Meeting Venue: For further information contact:

Committee Room 5, Tŷ Hywel Helen Finlayson

Meeting date: 10 May 2023 Committee Clerk

Meeting time: 09.00 0300 200 6565

SeneddHealth@senedd.wales

Private pre-meeting

(09.00 - 09.15)

1 Introductions, apologies, substitutions and declarations of interest

(09.15)

2 Gynaecological cancers: Panel 3

(9.15–10.30) (Pages 1 – 40)

Lowri Griffiths, Chair, Wales Cancer Alliance & Director of Support, Policy and Insight, Tenovous Cancer Care

Rachel Downing, Head of Policy and Campaigns, Target Ovarian Cancer Claire O'Shea, Person affected by cancer

Research Brief

Paper 1: Tenovus Cancer Care

Paper 2: Target Ovarian Cancer

Paper 3: Claire O'Shea

Break

(10.30-10.45)



3 Gynaecological cancers: Panel 4

(10.45–11.45) (Pages 41 – 43)

Dr Shanti Karupiah, Royal College of General Practitioners Dr Zohra Ali, British Islamic Medical Association

Paper 4: Royal College of General Practitioners

4 Papers to note

(11.45)

4.1 Joint letter to the Minister for Health and Social Services from the Health and Social Care Committee and the Public Accounts and Public Administration Committee regarding Betsi Cadwaladr University Health Board

(Pages 44 – 45)

4.2 Letter to the Deputy Minister for Social Services regarding the all-Wales hospital discharge policy and associated guidance

(Pages 46 - 47)

4.3 Letter to the Finance Committee regarding evidence provided by the Welsh Government as part of the scrutiny of the draft budget 2023-24

(Pages 48 - 50)

4.4 Letter from the Minister for Health and Social Services regarding Endoscopy services: follow up inquiry

(Pages 51 - 55)

4.5 Letter from the Minister for Health and Social Services regarding the Healthcare (International Arrangements) (EU Exit) Regulations 2023

(Pages 56 - 58)

4.6 Letter to the Finance Committee regarding health boards' financial sustainability and balance

(Pages 59 - 60)

4.7 Letter from the Finance Committee regarding health boards' financial sustainability and balance

(Pages 61 - 62)

- Motion under Standing Order 17.42 (vi) and (ix) to resolve to exclude the public from the remainder of this meeting and for all items other than items 1 to 3 at the meeting on 25 May 2023
- 6 Gynaecological cancers: consideration of evidence (11.45-12.00)
- 7 Health Service Procurement (Wales) Bill: Stage 2
 (12.00-12.05) (Pages 63 66)

Paper 5: Health Service Procurement (Wales) Bill: Stage 2

8 Endoscopy services: Welsh Government response
(12.05-12.15) (Pages 67 - 70)

Research Brief

By virtue of paragraph(s) vi of Standing Order 17.42

Agenda Item 2

Document is Restricted

Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor Iechyd a Gofal Cymdeithasol</u> ar <u>Canserau gynaecolegol</u>

This response was submitted to the <u>Health and Social Care Committee</u> consultation on <u>Gynaecological Cancers</u>

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 groupⁱ, Dr Louise Hanna at Velindre Cancer Centre.

Incidence of gynaecological cancers in Wales

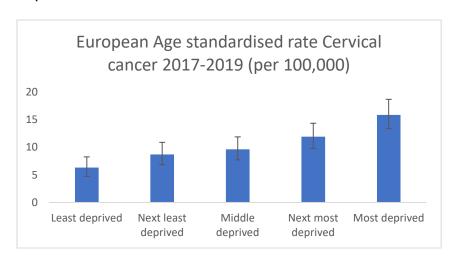
2019 (most recent data):

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 precancerous 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] 2021ⁱⁱ, 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.

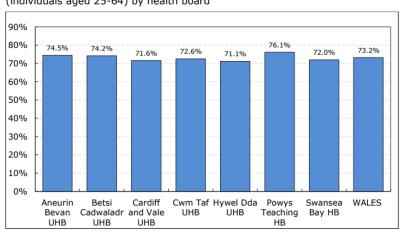
Moving forward, the biggest indicator of cervical cancer risk will soon become uptake of the HPV vaccine during the teenage years. Vaccine uptake in children in Wales is

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 2030ⁱⁱⁱ.

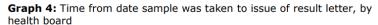
The Committee might want to ask NHS managers responsible for the HPV vaccine programme why there is variation in uptake of HPV vaccine between health boards. The HPV vaccine is the closest thing we've ever had to a "cure" for cervical cancer and Wales appears to experience a deprivation gap, an increasing 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?

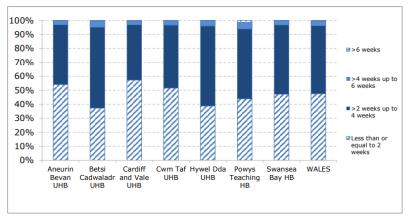
A research paper looking at HPV vaccine uptake in South-West England in 2021^{iv} indicated that written consent from parents was a barrier to uptake that could increase the deprivation gap but could be overcome by allowing parents to verbally consent and adolescents to self- consent.

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





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

i https://collaborative.nhs.wales/networks/wales-cancer-network/clinical-hub/cancer-site-groups/gynaecological-cancer/

https://wcpes.co.uk/scorecard following application of the Gynaecological cancers filter.

https://www.who.int/initiatives/cervical-cancer-elimination-initiative

https://bmjopen.bmj.com/content/11/7/e044980

v https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associateddocuments/gynae-nop-cervix-pdf/

https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associateddocuments/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-associateddocuments/gynae-nop-vulva-pdf/

https://collaborative.nhs.wales/networks/wales-cancer-network/clinical-hub/cancer-site-groups/

Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor Iechyd a Gofal Cymdeithasol</u> ar <u>Canserau gynaecolegol</u>

This response was submitted to the <u>Health and Social Care Committee</u> consultation on <u>Gynaecological Cancers</u>

GC 06

Ymateb gan: | Response from: Target Ovarian Cancer





Welsh Health and Social Care Committee- Gynaecological cancers Consultation

Information available and awareness of risk factors and symptoms associated with gynaecological cancers.

Over 300 women are diagnosed with ovarian cancer each year in Wales and more women die as a result of ovarian cancer in the UK than all other gynaecological cancers combined. As there is currently no screening tool for ovarian cancer, to improve early diagnosis it is vital that women are not only aware of the symptoms but also the importance of family history so they can contact their GP as soon as they begin experiencing symptoms.

Target Ovarian Cancer found that awareness of the key ovarian cancer symptoms remains worryingly low in Wales, with just 33 per cent of women able to name abdominal pain as a symptom, 27 per cent able to name bloating, 5 per cent able to name feeling full and just 1 per cent able to recognise urinary urgencyⁱⁱ.

Approximately 13 per cent of ovarian cancers are caused by a mutation of the BRCA1 or 2 geneⁱⁱⁱ. However, there is poor awareness among women across the UK of the importance of family history of cancer with only a third of women recognising that family history could be a risk factor for ovarian cancer.

Target Ovarian Cancer welcomed the development of a NICE guideline on inherited ovarian cancers, but a key area not covered in the guideline will be awareness of the risk. We need to see awareness campaigns alongside investment into better prevention options and access to genetic counselling so that those with a family history can make an informed decision about genetic testing.

The most effective way of achieving greater awareness is government funded symptom awareness campaigns. We must ensure that everyone is aware of the key symptoms of ovarian cancer. Concerningly, awareness of feeling full has declined from 5 per cent of women recognising this as a symptom in 2016 to just 3 per centiv. We urgently need to see government funded awareness campaigns across Wales that highlight the symptoms of ovarian cancer. In 2017 the Welsh Assembly Petitions Committee produced a report calling for a public facing ovarian cancer awareness campaign in Wales. To date there have been no specific awareness campaigns on ovarian cancer symptoms. The case for symptoms awareness is clear as our research also found that just 6 per cent of women in Wales said that they were very confident in naming ovarian cancer symptoms.

Awareness of symptoms is key to improving early diagnosis, however, we must also address the misconceptions around ovarian cancer. Target Ovarian Cancer found that 42 per cent of women in Wales wrongly believe that cervical screening detects ovarian cancer^{vi}. We need to ensure that the information provided at cervical screening appointments makes clear that it does not test or screen for other gynaecological cancers and include the symptoms of other gynaecological cancers.

Recommendations

- We need to see Government funded awareness campaigns across Wales that highlight the symptoms of ovarian cancer
- There needs to be campaigns that educate the public on the importance of knowing their family history so they can investigate preventive action
- Consideration should be given to ensuring that materials related to cervical screening are clear that it does not test for the other gynaecological cancers.

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.

If diagnosed at an earliest stage (Stage I), 93 per cent of women in Wales can survive five years or more, compared to just 13 per cent of women diagnosed at stage IV. VII Currently just over a third of women are diagnosed at an early stage in Wales VIII.

Once a woman has been referred by her GP for tests, it is vital that either ovarian cancer is diagnosed or ruled out as soon as possible. However, there can still be unnecessary delays in diagnosis. Ovarian cancer is diagnosed using a CA125 blood test, followed by an ultrasound if the levels are raised. The CA125 protein is elevated in 80 per cent of women with advanced disease, but no more than 50 per cent of women diagnosed with stage I ovarian cancer will have a raised CA125^{ix}. Having a CA125 as a standalone test can mean that women with early-stage disease are not referred.

We have also found that there are delays in waiting for test results despite GPs being able to access these tests directly. Target Ovarian Cancer found that one third of women in Wales reported waiting more than three months from their first appointment with their GP to receiving their diagnosis. Given the time taken to get the results of the CA125 blood test and an ultrasound, there is an urgent need to shorten the ovarian cancer diagnostic pathway

We need to see a reduction in the time it takes to get a diagnosis and ensure that more women with an early-stage cancer are identified. By carrying out the CA125 blood test and ultrasound concurrently as is currently done in Scotland, it would allow women to be diagnosed faster and begin treatment as soon as possible.

GP awareness is also key to early diagnosis. However, too many women experience misdiagnosis and delays as a result of GPs not being appropriately educated or supported to diagnose ovarian cancer. Target Ovarian Cancer found that 43 per cent of GPs in Wales believe that symptoms only present in the late stages of disease and one quarter of those diagnosed with ovarian cancer report visiting their GP three or more times before being referred for tests^x.

This is concerning, as symptoms are often present in those with early-stage disease. Appropriate training must be in place at primary care level if we want to ensure more people receive an early diagnosis.

Recommendations

- Shorten the diagnostic pathway for ovarian cancer so that a CA125 blood test and ultrasound are carried out at the same time
- Ensure that GPs are well supported with access to training, Advice and Guidance services vague symptoms pathways and support to use NICE guidance

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.

Target Ovarian Cancer welcomed the introduction of the Suspected Cancer Pathway in Wales and the 62-day target to receive a diagnosis and begin treatment. The pandemic had a drastic impact on urgent referrals for suspected cancer from GPs and treatment wait times. Early diagnosis and beginning treatment as soon as possible are key in increasing the survival rates among women with ovarian cancer.

In 2022 just 34 per cent of gynaecological cancers met the single cancer pathway target, when comparing this to those diagnosed with lung cancer 54 per cent of those diagnosed met the cancer pathway, starting their treatment within 62 days of first being suspected with cancerxi. Understanding why we continue to see delays in diagnosis for gynaecological cancers is crucial. We know that there are many barriers to an early diagnosis for ovarian cancer, such as misdiagnosis and a lack of GP awareness. We must see the pathways for gynaecological cancers prioritised to ensure more people meet the single cancer pathway target and are able to start treatment as soon as possible. Urgent action must be taken to ensure everyone diagnosed with ovarian cancer and other gynaecological cancers have the best possible chance of survival.

Recommendations:

 Prioritise gynaecological cancer diagnostic pathways. Consider reviewing and shortening the diagnostic pathway for ovarian cancer to ensure that it meets the single cancer pathway target.

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)

This audit will play a crucial role in transforming diagnosis and access to treatment for everyone diagnosed, irrespective of their age or where they live.

Target Ovarian Cancer welcomed the announcement that the full clinical audit to improve ovarian cancer care and treatment across England and Wales. It is vital that the commissioned audit provides in-depth analysis of the diagnosis and treatment of ovarian cancer so that progress can be tracked.

Where you live should not affect your treatment options or outcomes. It is vital that the NHS in Wales proactively identifies ways of tacking any disparity identified in the audit when it reports.

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.

Ovarian cancer is often reported as part of a larger set on gynaecological cancers. However, this is unhelpful as the diagnostic and treatment pathways for individual cancers, ovarian, cervical, womb, vulval and vaginal are different so it is difficult to make meaningful assessments of performance in ovarian cancer diagnosis and treatment using aggregated data sets.

Recommendation

 Datasets should be disaggregated by tumour type to ensure we can better understand how services are currently performing and plan interventions.

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.

We welcome the focus the Welsh Government is placing on women and girls' health and gynaecological cancers. However, the Cancer Quality Statement lacks detail on how the Government/NHS will specifically address symptom awareness and the variation in access to diagnostics and treatment for gynaecological cancers in Wales.

It is concerning that just 34 per cent of gynaecological cancers met the single cancer pathway target in Wales. To ensure 75 per cent of people diagnosed with cancer meet the 62-day target we need to see the current diagnostic pathway for ovarian cancer reviewed and shortened, this would allow women to be diagnosed faster and begin treatment as soon as possible.

The focus placed on screening will significantly help other gynaecological cancers such as cervical, however for ovarian cancer there is currently no viable screening programme. To see accelerated progress and achieve earlier diagnosis for everyone diagnosed with ovarian cancer in Wales the action plan needs to consider symptom awareness campaigns that feature the symptoms of ovarian cancer and other less common cancers.

Recommendations

- We need to see continued commitment to improve early diagnosis and treatment of gynaecological cancers
- Ensure that GPs are well supported with access to training and symptom awareness, helping more women presenting with symptoms get diagnosed earlier

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.

Research is vital to improving the outcomes for everyone diagnosed with ovarian cancer. However, in recent years we have seen a worrying decline in the UKs spend on ovarian cancer research. Public spend on ovarian cancer research across the UK has decreased by 27 per cent in ten years, from £12.9m in 2010/11 to £10.3m in 2020/2, which is just 3 per cent of site-specific research. This is concerning as the outbreak of coronavirus also saw many medical research charities struggling to retain their funding with £270 million cut from charitable research spend.

One in ten women are diagnosed with a less common tumour type^{xii}, however, rarer subtypes of ovarian cancer have fewer treatment options. When considering how we can improve the treatment offered to everyone with cancer, we must ensure that rarer tumours along with other rare and less common gynaecological cancer types receive the focus and funding they need, so everyone has the best possible chance of survival.

Clinical trials offer those diagnosed with cancer the opportunity to access new cancer drugs and treatment options. This is particularly important for those diagnosed with rarer tumours

or incurable ovarian cancer. Our recent Pathfinder study highlighted that there has been a 10 per cent decline in women being asked about clinical trials between 2016 and 2022. This is despite there being a clear desire to take part in clinical trials with 61 per cent of women who took part in our study and who were not asked to take part in a clinical trial, saying they would have liked the opportunity to take part in a trial^{xiii}. We must ensure that the decline in opportunities to take part in trials is reversed and information about clinical trials is shared.

Target Ovarian Cancer welcomes the commitment outlined in the Cancer Quality Statement that all eligible patients will be offered access to research trials and that Wales will provide supporting infrastructure for cancer research. This is crucial if we are to continue developing lifesaving treatment and new diagnostic tools.

Recommendations

- Patients must be empowered to ask about clinical trials, with signposting to information on clinical trials embedded into interactions between patients and their clinical team.
- We need to see urgent investment in post pandemic studies that will lead to better treatments.

The priority given to planning for new innovations (therapy, drugs, tests) that can improve outcomes and survival rates for women.

No matter where they live or their personal circumstances everyone diagnosed with ovarian cancer must have access to specialist support and the best treatment. We welcome the commitment made in the Cancer Quality Statement to ensure more evidence-based surgical techniques, radiotherapies and genomic testing are routinely available. Everyone with ovarian cancer must be able to access the best possible treatment, targeted to their needs.

Surgery is the treatment that offers the best prognosis. Ovarian cancer surgery is a complex, major operation so it is vital that surgery is undertaken at a specialist multidisciplinary disciplinary diagnostic centre. Research has shown that treatment at specialist centres improves survival by 45 per cent^{xiv}.

Genomic testing

The availability of PARP inhibitors to treat the most common type of ovarian cancer is dependent on the presence of a BRCA variation or HRD status which is determined through genomic testing. The presence of a BRCA germline variant also has implications for family members as they may also have the gene, so women need the right support when undergoing BRCA germline testing.xv

We found that there is good access to genomic testing in Wales of those we surveyed:

- 79 per cent had BRCA germline testing
- 42 per cent had BRCA somatic testing
- 8 per cent report HRD testing (available across the whole UK from December 2021)

However, 65 per cent said they weren't offered specialist counselling to help them decide if they wanted to be tested.

Recommendations

• Everyone that would benefit from specialist surgery must be able to access it regardless of age or geographical location.

 There must be a consistent approach to consenting for genomic testing, with access, where required, to genetic counselling maintained for those having BRCA germline

<u>Times/Monthly/suspectedcancerpathwayclosedpathways-by-localhealthboard-tumoursite-agegroupgender-measure-month</u>

ⁱ Cancer Incidence in Wales, 2002-2019 - Public Health Wales (NHS, Wales)

ⁱⁱ Target Ovarian Cancer, Awareness Measure. (2022)

Pathfinder 2016: Transforming futures for women with ovarian cancer.

iv Target Ovarian Cancer, Awareness Measure. (2022)

^v Target Ovarian Cancer, Awareness Measure. (2022)

vi Target Ovarian Cancer, Awareness Measure. (2022)

vii Welsh Cancer Intelligence and Surveillance Unit Cancer survival by stage of diagnosis. Available at: www.wcisu.wales.nhs.uk/cancer-survival-by-stage-at-diagnosis-in-1

viii Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

^{ix} Scottish Intercollegiate Guidelines Network (2013) SIGN 135. Management of epithelial ovarian cancer. Revised 2018. Available at: www.sign.ac.uk/sign-135-management-of-epithelial-ovarian-cancer.html

[×] Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

xi StatsWales: Cancer Waiting Times. https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-

xii Target Ovarian Cancer's data briefing on Ovarian Cancer. 2018. Available at: https://targetovariancancer.org.uk/sites/default/files/2020-07/Target%20Ovarian%20Cancer%27s%20data%20briefing%20for%20ovarian%20cancer%20in%20

xiii Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

xiv Khoja, L., et al. 'Improved Survival from Ovarian Cancer in Patients Treated in Phase III Trial Active Cancer Centres in the UK'. Clinical Oncology (Royal College of Radiologists (Great Britain)), vol. 28, no. 12, Dec. 2016, pp. 760–65. PubMed, https://doi.org/10.1016/j.clon.2016.06.011.

^{xv} Pathfinder Wales 2022: Faster, Further, Fairer (2022). Target Ovarian Cancer.

Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor Iechyd a Gofal Cymdeithasol</u> ar <u>Canserau gynaecolegol</u>

This response was submitted to the <u>Health and Social Care Committee</u> consultation on <u>Gynaecological Cancers</u>

GC 11

Ymateb gan: Claire O'Shea | Response from: Claire O'Shea



13th January 2023

Ref: Gynaecological cancer consultation

Dear Chair.

I am submitting evidence as an individual who at 40 years old had a diagnosis of Uterine Leiomyosarcoma (uLMS) in November 2022. The resulting treatment was a full hysterectomy in December. I am currently under the care of the Women's Cancer Centre for Wales at University Hospital Wales.

For the purposes of brevity, I have attempted to link my experiences to research and wider issues for people diagnosed with uLMS. There are many more significant issues to cover, and I would be very happy to develop these further in writing or in person, if the committee would find it useful. Uterine Leiomyosarcoma is a rare and aggressive cancer; because of this it is often diagnosed late, leading to devastating consequences. If awareness, attention and research were achieved, many cases could potentially be prevented or cured. Too many patients end up having palliative care soon after diagnosis.

Background

In July 2021 I began suffering with symptoms of Uterine Leiomyosarcoma, a rare and aggressive cancer that has a poor prognosis and a high recurrence rate. It makes up less than 2% of all cancers; around 5300 people a year are diagnosed in the UK. The 5-year survival rate is 50%–55% for patients with early uterine sarcoma and 8%–12% for advanced cases. Due to lack of awareness of this cancer by both medical professionals and people presenting with symptoms, many cases are diagnosed late; this combined with low levels of research lead to extremely poor outcomes.

Since August 2021, I have struggled to get a diagnosis and timely treatment. When I first presented with symptoms; including a lump in my abdomen, my GP diagnosed me with Irritable Bowel Syndrome, as a result of a narrow set of questions about my symptoms. This resulted in months of delay. When dealing with sarcoma, fast diagnosis is one of the most important factors in reducing mortality. This is a common experience with Sarcoma, most GPs will only see one sarcoma in their career. The later sarcoma is diagnosed, the worse the outcomes, despite this, on average sarcomas are diagnosed when they are the size of a can of beans.

Over a few months, I made several attempts to get a follow up appointment; as the medication I was prescribed wasn't working. My symptoms were developing and it became

clear to me that the lump I had been able to feel in my abdomen was located in my uterus. I was increasingly alarmed. Eventually, I insisted on seeing a woman GP having heard a discussion on research that concluded patients who were treated by women healthcare professionals had significantly better outcomes. Following a consultation with the new GP, I was referred urgently to University Hospital Wales where, following scans, I was diagnosed with a suspected fibroid. I had several appointments to discuss treatments and to receive hormone injections to induce chemical menopause aimed at shrinking the 'fibroid' (which was now so large it was visible protrusion from my abdomen). Following the hormone injections, I was scheduled for surgery in July 2022, however due to the 'non-urgent' nature of a fibroid and the pressures experienced by the NHS my surgery was eventually performed at the end of September 2022.

Following my surgery (open myomectomy) I was advised that I would be contacted within 3 weeks if my biopsy results showed anything of concern. After 3 weeks, I assumed I had a clean bill of health and returned to work. However, again, due to the current pressures on the Welsh NHS I didn't get my results for 6 weeks. Sadly, on the 18th November 2022, I received the results of my biopsy, which showed the fibroid was uLMS. I was immediately sent for a CAT scan to see if the disease had spread to my lungs or other areas of the abdomen. The scans showed no evidence of tumours anywhere else in my abdomen. Shortly after the scans, I underwent a full hysterectomy on the 2nd December 2022. Although there were no signs of the cancer having spread, it was vital to have the procedure as a preventative measure due to the recurrence rates.

To date, I have only had surgery, as this is the most <u>effective way of treating sarcoma</u>. I am now under a three-monthly regime of x-rays, scans and a consultant appointment, as <u>recurrence rates are between 53% and 71%</u>. Alongside this I am still waiting on the results of whether the cancer cells were hormone receptive, if this is the case I will need another procedure to remove my ovaries; which I was reluctant to do without establishing the histology of the cancer, due to the negative impact of early menopause.

Through my experience as summarised above and in reference to some of the specific areas the committee are interested in receiving evidence on, I consider the following evidence and information to be of particular importance.

Awareness and information

• Information and awareness are very low. 75% of people surveyed by Sarcoma UK said they didn't know what sarcoma was. My symptoms presented as a fibroid, an extremely common condition in women. Personally, I wasn't aware of fibroids as a condition despite considering myself to be well informed and educated on women's health. My GP misdiagnosed me with IBS due to the impact the fibroid was having on my digestive system, even with an abdominal exam where the growth was easy to feel. If I had better awareness of the condition, I would have been better able to advocate for myself, and link the developing symptoms to specific conditions.

• 40% of sarcoma patients do not receive an accurate diagnosis, and on average sarcoma patients wait an average of 92 weeks between spotting symptoms and being referred for investigation. This can be longer in the case of uterine sarcoma, as other soft tissue sarcomas appear in the extremities and can be more obvious due to the proximity to the surface. I waited for approximately 66 weeks, but my consultant said that was largely due to the fact I didn't carry excess weight on my abdomen and the growth was visible at an earlier stage.

Primary Care

- There were many issues with primary care, alongside the initial incorrect diagnosis. I was given blood tests at my initial consultation. When they came back as negative, I was not contacted, and had to call my GP surgery a few weeks later. I was not offered further diagnostics, despite my symptoms worsening and the medication for IBS not improving the situation. Over the phone I was simply offered a prescription for a new medication.
- I was unable to secure appointments as the econsult system my surgery has employed did not give me the opportunity to connect some of the symptoms I was experiencing together. Initially I had not recognised it as a gynaecological condition, as the main impact was on my digestive system and bladder. This often bounced me between calling my pharmacist or attending A&E depending on the pathway of symptoms This led to frustration and giving up due to the time-consuming nature of it.
- I was made to feel like I was being neurotic. Despite being very concerned about my health, I was met with indifference at every phone call and appointment. On one occasion I called about a 'growing lump' and was told to monitor it and get in touch if I felt like it was growing. The basis of the phone call was that I already knew it was growing. It is nearly impossible to personally monitor the growth of an internal lump in an accurate way. My experience is not unique, Sarcoma UK research says 27% of patients who visited their GP were started on treatment for another condition or told that their symptoms were not serious.
- When I finally had an appointment with a GP, who referred me for an ultrasound, I cried with relief having finally felt my concerns were taken seriously. She was empathetic and clearly concerned, and I ended up in hospital for scans two working days later. Feeling relief at getting a standard of care that should be available as standard is also something that other women have spoken to me about.
- I do not know what my long-term prognosis is at this stage, uLMS is under researched and unpredictable. Regardless, my mental health has been severely impacted, knowing how high recurrence is, and how long it was left to grow in my body and that it was staged as aggressive as a result. My GP has not contacted me since my diagnosis or offered me support outside of the hospital treatment I have received.

Diagnostics and cancer backlogs

- <u>uLMS</u> is commonly misdiagnosed as fibroids, as there is little to no difference when viewed on MRI or Ultrasound. Most cases of Uterine Sarcoma are discovered as a result of a routine hysterectomy or myomectomy to remove a fibroid. This was my experience and is very common as there are no reliable preoperative diagnostics. I waited from February 2022 until the end of September 2022 until I was able to have surgery. This was an additional 8/9 months where the sarcoma had an opportunity to spread and progress to Stage III.
- Fibroid surgery is considered 'non-urgent' (despite them having an enormous impact on wellbeing) and while this is understandable, without being able to differentiate between a sarcoma and a fibroid, the delay can have a catastrophic impact for women who are eventually diagnosed with uLMS (and other gynaecological sarcomas)
- Many people are offered other treatments for fibroids including uterine artery embolization. Indeed, I was offered this as the preferred treatment by my consultant. If I had taken this option the sarcoma would have been left in my body undiagnosed. Many women find themselves in this situation; research shows that it can postpone diagnosis by an additional 13-15 months. While uLMS is rare, the risk and impact of sarcoma cannot be understated when women are advised on their treatment options. I opted for surgery following personal research based on the need for more frequent reinterventions after UAE and long-term studies on the women's reported wellbeing following both procedures. However, I was nervous about expressing this decision against my consultant's recommendation. She was, however, very supportive and pleased that I had undertaken research from credible sources.
- Despite the significantly better treatment I received in hospital, there were still delays and dismissal of my experiences. I had two hormone injections to put me into chemical menopause to shrink the 'fibroid' to improve the outcomes at surgery. When the hormone injections wore off, the fibroid grew back rapidly. I called the obs-gynae department 79 times over 3 days to report my concern, but the phone was not answered. I made an official complaint in writing, expressing my concerns about the rapid growth and the lack of communication about my surgery. When someone eventually called me back, I was made to feel like I was lying about the rapid growth in order to secure a surgery date (after my original slot had been missed) At no point was I able to speak to a medical professional or asked to return to clinic to establish whether my 'fibroid' had grown rapidly. My concerns were 'dealt with' by administration staff. This was another occasion when I ended up crying to an administrator about the pain and impact on my wellbeing. The rapid growth should have also been a 'red flag' and potentially my surgery should have been changed from a myomectomy to remove a fibroid, to a hysterectomy due to risk of uLMS.

Research and breakthroughs

- Most charities and professionals working on sarcoma will tell you that research and breakthroughs on sarcoma are inadequate. It is a rare cancer, and even rarer when it appears in the reproductive organs. I have had to make life changing decisions based on research with 75 participants which hasn't been updated for years. On issues like keeping my ovaries in to prevent the conditions associated with early menopause, I have had to do it with an inconclusive research base and against the advice of my medical team, who ultimately were concerned with the immediate threat to life my cancer poses, as opposed to my long-term wellbeing should I survive the current diagnosis.
- If surgery for uLMs isn't successful and the cancer spreads, research into effective chemotherapy and radiotherapy has yet to lead to a consistently-effective standardised treatment pathways So in most cases the cancer is treatable rather than curable.
- Basic research hasn't established conclusive knowledge and is widely debated.
 Having been diagnosed with a fibroid (a common pathway to discovering sarcoma);
 there isn't conclusive research to say whether fibroids become cancerous, or whether the growth is cancerous from the start. This speaks volumes about the priority given to women's health. The 5-year survival rate for testicular cancer is 95% It is hard not to consider how the gap in research has led to such radically different outcomes.
- Recurrence levels are high, as is metastasis. This is both because of delays in diagnosis, but recurrence can happen many years after the primary tumour and it is not clear why this happens. With other cancers there are blood tests and other ways of monitoring, with uLMS it is visual monitoring on a 3-monthly basis, to ensure surgery can be deployed early as surgery is the most reliable method of controlling the disease.

Personal Impact

Several opportunities to diagnose me early and offer me timely treatment were missed. At the conclusion of my treatment at the end of December, the cancer cells appeared to be limited to my uterus. However, this is not reassuring. uLMS is under researched and as a result recurrence levels are high and prognosis once it has metastasized is extremely poor. It is very isolating to read about the lack of research and treatment for a condition that is likely to recur.

It is a rare cancer, but unfortunately the consequences are catastrophic. The current approach to diagnosing this condition always feels though it focuses on 'most likely; and 'best case' scenarios, to the extent that indicators of seriousness that should have set alarm bells ringing were ignored or weren't understood as significant.

I have had two major surgeries in 3 months, I am no longer able to have children, I am likely to experience early menopause and need to deal with the trauma of the last few months. I have taken significant amounts of time off work, and this will be ongoing as I am on a regime of a scan, x-ray and consultant appointment every three months for the next two years. At the two year point my scans will be done on a 6-monthly basis. I have no peace of mind and the constant looming of check-ups, means I have to plan my life accordingly and try to avoid

'scan-xiety'. I have been reassured that I will be treated with priority due to the nature of the cancer and the care provided to me by the gynae-oncology nurses and the consultant team has been personal and empathetic. I can't criticise their professionalism at all. However, due to the enormous pressure the Welsh NHS is under, I am still struggling to contact staff at University Hospital Wales to arrange appointments. I have called for results of the histology report on my cancer, and even though the original procedure was on the 30th September I do not know whether my cancer is hormone responsive - which would entail another procedure.

I live with the knowledge that due to the length of time I have had this condition and the speed at which the Welsh NHS is currently operating, my chances of dying of this cancer are high. It is hard not to feel completely isolated, as well as having my trust in the process eroded. I spend a great deal of my time thinking about the very real prospect that even with the radical surgery I have undergone at 40, the probability of me dying of this cancer still remains high.

Recommendations

Recommendations for further research and service provision can be found via charities like Sarcoma UK and Cancer Research UK. I would recommend reading their policy positions, as it will be systemic and focus on wider experiences. As a person experiencing this cancer in Wales my recommendations would include.

- Improvement of early diagnosis through primary care education; early diagnosis is key to better outcomes.
- Increased public awareness of uLMS in order that people present with symptoms much earlier.
- National Standards for Sarcoma Services were published in 2009, I have been unable to find a copy as all online links are broken, including in the <u>Service</u> <u>Specification CP149 Soft Tissue Sarcoma</u>. These should be reviewed and updated with current research.
- Diagnosis of uLMS must be improved. The risks of assuming a fibroid is benign are catastrophic. All fibroid surgery should be treated with urgency if outcomes are to be improved. In order to achieve a solution, proportionate to the risk, research into preoperative diagnosis should be funded and prioritised as a matter of urgency.
- Resources should be channelled towards general research into sarcoma. Diagnosis
 rates are increasing and with little understanding of the causes, it is hard to ensure
 rates do not continue to increase.
- There should be a cultural shift within the NHS (and wider society) into how women are treated when they present with symptoms. I was dismissed on more occasions than I care to remember. I began to refer to it as 'medical gaslighting' My worst fears were eventually realised. My experience since then has not improved and there has been little contrition or a process to educate and reform practice. My GP has yet to get in touch despite my serious diagnosis in November. Alongside a better response to women and their health concerns, primary care must have better mechanisms for learning from mistakes, which involve the patient.

I am pleased to see the attention of the committee being turned towards gynaecological cancers, it has been helpful to channel some of my experiences into this response. I hope as a result there are improvements for people experiencing the impact of gynaecological cancers in Wales.

Yours faithfully.

Agenda Item 3

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

This response was submitted to the <u>Health and Social Care Committee</u> consultation on **Gynaecological Cancers**

GC 04

Ymateb gan: | Response from: Coleg Brenhinol Meddygon Teulu | Royal College of General Practitioners





Gynaecological Cancer Consultation Response RCGP Cymru Wales

In response to the Senedd's request for comment regarding gynaecological cancers, RCGP Cymru Wales has consulted with its GP members and patient representatives to ascertain the present position on this topic in general practice. The issues raised related to awareness, screening, women's health, onward referrals, and the impact of COVID-19.

1. Awareness

Both patient representatives and GP members agree that awareness on the topic of gynaecological cancer is not at desired levels. Patients in particular note that they have access to information regarding cervical cancer but are not aware of any symptoms of other cancers such as ovarian cancer. GPs also do not feel patients presenting with symptoms know that they may be symptoms of these cancers.

2. Screening programmes

The prevention strategy with which GPs have greatest involvement with is the cervical smear. GP members note there is confusion within the public regarding who is entitled to a smear test how often. RCGP Cymru Wales is aware that some members of the public believe a smear test is only for people with symptoms, while the differences between the age of patients who qualify for smears and the regularity of the tests between the four nations means that well-meaning publicity often adds to the confusion.

GPs report an anecdotal decline in women booking themselves in for smear tests. They report reasons ranging from embarrassment, busy lifestyles and cultural beliefs.

RCGP Cymru Wales is aware of public campaigns to normalise the discussion and process surrounding a smear test however, the risks are not highly publicised. Since the introduction of HPV vaccine and the waning of the 'Jade Goody effect' there is a concern that cervical cancer is not as prominent as it could be in the public perception¹. A Public Health Wales study in 2014 reported that women who have received the HPV vaccine are less likely to attend a screening², it seems further research into the uptake in Wales is needed.

3. Women's health

Patients also raise concerns that, while much has been done to promote women's health, particular training regarding all aspects is still needed to ensure that health professionals

¹ Sky News, 2019, Cervical Smear Campaign Launched: https://news.sky.com/story/cervical-smear-campaign-launched-as-jade-goody-effect-wears-off

² Public Health Wales, Study of the HP plack parties 344, https://ncphwr.org.uk/portfolio/hpv-immunisation-wales/

understand that presentation of serious conditions in women. They draw parallels with discoveries regarding late diagnosis of endometriosis, which has been recently publicised. ³

4. Referral to secondary care

When asked about referrals for gynaecological cancer symptoms, GPs note that referral times vary hugely between geographic locations and are often thought to be less urgent than other, more widely publicised cancers such as breast and lung.

5. Impact of COVID-19

GPs also raise the impact of COVID-19 on both the screening and referral process, noting the backlog. One GP states that prior to COVID-19 women presenting with postmenopausal would be seen in a matter of weeks, while now that wait is likely to take months. Our members also note that patients are now out the habit of booking routine screenings due to the postponement of them during COVID-19.

³ NIHR, Why do women feel unheard, Novembe മൂറ്റ് വ്യൂട്ടി വാര്യം വാര്യം Novembe മൂറ്റ് വാര്യം വാര്

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Health and Social Care
Committee

Y Pwyllgor Cyfrifon Cyhoeddus a Gweinyddiaeth Gyhoeddus

Public Accounts and Public Administration Committee

Eluned Morgan MS

Minister for Health and Social Services

19 April 2023

Dear Eluned

Betsi Cadwaladr University Health Board (BCUHB)

At our meetings on Thursday 30 March, the Health and Social Care and Public Accounts and Public Administration Committees both considered issues relating to Betsi Cadwaladr University Health Board and any possible Committee actions. While both Committees are concerned about the situation, we want any Committee involvement to be timely and to add value. We are keen to avoid duplication, and will work together where appropriate to achieve this. We are also mindful of the impact the current situation is having on the staff of the health board.

We have there agreed to return to the issue, and any possible Committee actions, at our concurrent meeting on 25 May. To help inform our discussion, we would be grateful if you could provide the information outlined in the annex to this letter. We would welcome a response by 12 May 2023.

Yours sincerely

Russell George MS

Chair, Health and Social Care Committee

Mark Isherwood MS

Chair, Public Accounts and Public

Administration Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.



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Annex: Betsi Cadwaladr University Health Board (BCUHB)

Following consideration on 30 March 2023 by the Health and Social Care and Public Accounts and Public Administration Committees of the situation at Betsi Cadwaladr University Health Board, we would welcome information on the matters listed below. We would be grateful to receive your response by 12 May 2023.

- 1. Additional information on the Intervention and Support Team including its appointment, terms of reference, methods of working, time commitment, and relationship with Welsh Government and the new NHS Executive.
- 2. An update on the work and progress against objectives identified under the new special measures regime introduced in BCUHB.
- 3. A timescale for the work looking at improving accountability, as well as that on revising and refreshing the intervention and escalation framework.

In relation to points 2. and 3. above, the Committees would welcome six monthly updates on progress in these areas.

Ağeyidər İrceyid 4.2

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Julie Morgan MS

Deputy Minister for Social Services

Welsh Government

21 April 2023

Dear Julie

All-Wales hospital discharge policy and associated guidance

Recommendation 3 in our <u>report</u> on the Welsh Government's draft budget 2023-24 asked for information about how long the revised guidance issued on 30 December 2022 that patients may be discharged while waiting for a social care assessment or without a care package being in place was expected to remain in effect.

In your <u>response</u> to our recommendation you clarified that the letter issued in December 2022 was "in support of existing discharge guidance already available in the system", and would therefore "remain extant for the foreseeable future"

We note that the 'Delivering optimal outcomes and experience for people in hospital' guidance, which forms part of the Six Goals for Urgent and Emergency Care Programme, states:

"The all-Wales discharge policy is being updated (2022) and should be used to support the transfer of patients once they are clinically optimised and can move to a more suitable place of care. Their next stage of care should be identified by the D2RA pathway that they are on.

There are two new pieces of guidance that will be available which will support this framework and become part of the updated discharge policy:

- Trusted Assessor role guidance.
- Reluctant discharge guidance."

We would be grateful if you could:

- 1. Provide information about when the updated all-Wales discharge policy, and the new guidance regarding the Trusted Assessor role Reluctant discharge will be published.
- 2. Commit to providing us with copies of all three documents when they are available.

We would be grateful for a response by 9 June 2023.

Yours sincerely

Russell George MS

Lessell George

Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.



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Peredur Owen Griffiths MS Chair Finance Committee

28 April 2023

Dear Peredur

Scrutiny of the Draft Budget 2023-24: Evidence provided by the Welsh Government

Thank you for your letter of 8 March 2023, and the opportunity to comment on the budget documentation provided by the Welsh Government to inform the Senedd's scrutiny of the Draft Budget 2023-24.

We discussed your letter at our meeting on 30 March 2023, and hope that the reflections on our experience of scrutinising the Welsh Government's draft budget 2023-34 set out in the annex to this letter will be of assistance in driving forward improvements for future years.

Please let us know if you would like any further information.

Yours sincerely

Russell George MS

Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.

Annex: views of the Health and Social Care Committee on the Welsh Government's Draft Budget 2023-24 documentation and subsequent Ministerial written evidence

Background

1. The Committee's scrutiny of the Welsh Government's draft budget 2023-24 took place on 11 January 2023. In line with our usual practice, we wrote to the Ministers with responsibility for health and social care on 28 October 2022, requesting written information to inform our scrutiny. The deadline for submission was 14 December 2022. We received the final documentation in English on 21 December 2022. The Welsh documentation was not received until 9 January 2023 (our meeting papers had been published on 6 January 2023). In addition, on 9 January 2023, we received a request to replace part of the original English submission (which had already been published) with a revised version.

Timeliness of evidence

2. Papers need to be received bilingually when requested with all the relevant attachments. They should also be accurate and not need to be replaced by updated or amended versions. Receiving evidence a week late, and only just before the Christmas break, reduced the time available for Members and our officials to consider the evidence and prepare for the oral evidence session with the Ministers.

Focus of evidence

- **3.** The Committee would like to see the Welsh Government give us the top line, key messages; how the allocations reflect those messages; the outcomes they expect to see and how they will measure those outcomes. While we had written to the Welsh Government in advance to identify some issues, the written evidence was very long and lacked specifics.
- 4. In future, we would want a summary of key headline messages, key and significant changes (e.g. health board inflation increases, increase in social care funding), key pressures, key new objectives or priorities, and changes from the previous year. The main body should be well-edited and focused. It should show precisely what is being spent, in what areas, the timeline for the spend, and what impact/output will be secured for that spend. For capital schemes, it should be specific about what schemes are being funded, and what will be bought and by when. Evidence this year, and in previous years, has lacked granular detail.
- **5.** A significant proportion of health funding is given directly to health boards. The Committee needs to receive information about the Ministers' priorities and any directions relating to this funding at a far earlier stage. We can see no reason why we should not receive this at the same as health boards, and at the very least well in advance of any oral evidence sessions.

- **6.** The Welsh Government needs to be clearer in its budget narrative and documentation about how spending in other DELs contributes to tackling health inequalities. This should be clear in terms of messaging, and in terms of identified money, outcomes and measures.
- **7.** This is also the case in relation to preventative spend.

Welsh Government's response to the Committee's report

8. The Welsh Government's response to the Committee's report needs to be received further in advance of the Plenary debate to enable Members and stakeholders to consider it before taking part in the debate and vote on the budget. This year, we received the English version the evening before the debate, and the Welsh version and a covering letter just hours before the debate took place.

Information about the final budget

9. When the final budget is laid, it should be accompanied by clear information about what has changed from the draft budget. Ministers should write to Committees that have undertaken budget scrutiny, either to confirm the draft budget allocations are reflected in the final budget, or to identify where there have been changes.

Eluned Morgan AS/MS
Y Gweinidog lechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



Russell George MS Chair, Health and Social Care Committee

SeneddHealth@senedd.wales

25 April 2023

Dear Russell

Thank you for your letter of 10 March regarding the Committee's follow up to its inquiry into endoscopy.

The sustainability and professional accreditation of endoscopy services continues to be a priority for the Welsh Government. As I set out in my previous response to the Committee on this matter, there has been significant disruption to the national programme of work to support NHS organisations. Nonetheless, we continue to work with the NHS to make progress and to align this work with the Diagnostic Board. I announced earlier today the Diagnostics Recovery and Transformation Strategy, which aims to improve access to diagnostic tests and support the development of our diagnostic workforce. This new Strategy will build on, and incorporate, the work of the National Endoscopy Programme, providing opportunities to align with crucial wider developments such as the proposed regional diagnostic hub for southeast Wales.

I have responded to your Committee's recommendations below.

Recommendation: The Welsh Government should provide further information about the establishment of the NHS Executive. This should include details of its governance arrangements, its role and responsibilities in relation to holding health boards to account and ensuring that change is implemented, and the timescales within which it will take up those roles and responsibilities.

As you will know, the NHS Wales Executive became operational from 1 April 2023: Home-NHS Wales Executive. The National Endoscopy Programme forms part of the overall National Diagnostics Programme and the governance arrangements between national programmes and the NHS Wales Executive will be determined by the senior leadership team.

Working on behalf of the Welsh Government, the NHS Wales Executive's role is to provide strong leadership and strategic direction, and enable support and, where necessary, intervene to ensure the delivery of national priorities and standards and safeguard and

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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.

improve the quality and safety of care. The NHS Wales Executive will provide additional capacity at a national level to oversee and support delivery of these priorities by bringing together the NHS Wales Health Collaborative, NHS Wales Delivery Unit, NHS Wales Financial Delivery Unit and NHS Wales Improvement Cymru. The NHS Wales Executive will operate under a dedicated senior leadership team and will continue to provide many of the functions originally delivered by these organisations but in a more effective, efficient, and collaborative way. The NHS Wales Executive will:

- Strengthen national leadership and support for quality improvement.
- Provide more central direction to ensure a consistent and equitable approach to national and regional planning based on outcomes.
- Enable stronger performance management arrangements, including capacity to challenge and support organisations that are not operating as expected.
- Lever and respond to the advances in medicine science and technology to deliver a modern NHS in Wales.

Establishing the NHS Wales Executive will not change statutory accountability mechanisms. All NHS organisations are already directly accountable to Ministers, and the Welsh Government, and this will continue to be the case. Ministers will continue to set priorities, targets, and outcome measures for the NHS in the form of the NHS Planning Framework. This has been translated by the Director General for Health and Social Services/Chief Executive of NHS Wales into a Mandate to the NHS Wales Executive, setting out its role, ways of working and functions in the delivery of the expectations detailed in an annual Remit Letter.

During 2023, the intention is to build on this first phase of its establishment and strengthen the arrangement by incorporating further functions as part of the phase 2 programme. April 2023 - March 2024 will be a transitional year for the NHS Wales Executive and it is accepted that some elements of its development and its full effectiveness will continue to evolve over time as it matures and settles into the wider health and social care system.

Recommendation: The Welsh Government should provide us with an update by July 2023 on the development of the academy of clinical endoscopy, in particular to identify whether work is on track to meet the timescales envisaged in the cancer improvement plan for NHS Wales for 2023-2026.

Health boards in southeast Wales continue to develop proposals for endoscopy facilities that can accommodate the growing demand in this clinical service. Discussions are ongoing with clinical colleagues, including a Clinical Endoscopy Summit scheduled for 21 April to consider the most effective model for future service delivery. In parallel, Health Education and Improvement Wales is considering how the establishment of a Clinical Skills Training Academy model for endoscopy can be introduced to aid in both recruitment and retention of clinical endoscopists.

Recommendation: The Welsh Government should set out what actions will be taken, and when, to move endoscopy services from the current position, which is reliant on short-term measures such as insourcing and outsourcing to meet demand, and to free up money to invest in more sustainable workforce and capacity solutions.

The Welsh Government continues to work with health boards on the development of their endoscopy capacity. The national endoscopy programme has supported health boards to develop their demand and capacity modelling. Health boards are planning their services in response to this, and we are reviewing their local and regional plans. These involve a mixture of solutions, such as amended job planning, additional recruitment, training existing staff, and developing new facilities. I would like to draw attention to the Welsh Government's capital investment in new and refurbished endoscopy theatres in Cardiff and Newport as an example of Welsh Government support, but it will take many years for NHS bodies to recruit, train and deploy the required additional workforce capacity.

Most health boards will remain reliant on non-core staffing solutions to meet their population's overall need. It is likely that this will continue alongside the development of additional core capacity for some time, and this will depend on the pace at which staff can be recruited or trained – as well as future changes in the balance of demand/capacity and the future financial outlook for NHS Wales. The intention is to reduce the reliance as much as possible on outsourcing and to some extent on insourcing and waiting list initiatives. However, there will always be a need for a more limited use of this capacity to meet surges in demand or accelerate the rate of backlog reduction.

The intention is to develop core service capacity to the point where this can meet the vast majority of regular demand. As part of this, the national endoscopy programme is collaborating with Health Education and Improvement Wales (HEIW) to train cohorts of clinical endoscopists. So far HEIW has delivered three successful cohorts and eight clinical endoscopists have completed the training. There are three clinical endoscopists currently in training, with a further cohort to commence in September. The national endoscopy programme has also launched a UK wide attraction campaign to attract healthcare professionals to work in endoscopy in Wales. The Programme is currently undertaking a retention survey of all endoscopy staff within NHS Wales to get a better understanding of their experience within the workplace and ascertain the reasons for those choosing to leave or stay in the profession. The Programme will work closely with HEIW to develop an endoscopy specific retention plan to address any issues identified in the survey. We are also exploring the potential for the introduction of an endoscopy academy to support more rapid development of the future workforce.

Recommendation: In its response to this letter, the Welsh Government should set out what work is being done to understand and address barriers associated with variations or overly-restrictive health board HR policies that may prevent NHS staff from working or training in a health board other than the health board in which they are based. If more time is needed to respond, the Welsh Government should commit to providing this information by July 2023.

In the National Workforce Implementation Plan published in January, we have committed to address the barriers which currently prevent flexible deployment of staff across organisational barriers. Specifically, we have set out an action to support NHS Wales Shared Services to develop a 'passport' approach to enable more responsive, deployment of the workforce across NHS Wale organisations. We also commit in the plan to support the

need to plan and deliver services regionally as new and sustainable service models are developed.

Recommendation: In the response to this letter, the Welsh Government should set out what actions are being taken, and when, to lead, encourage and facilitate the uptake of innovative technologies and ways of working in endoscopy services in Wales.

Innovation in endoscopic care is an important component of improving services. In recent years, endoscopy services have integrated many innovations such as improved imaging, flexibility, lighting, and capabilities such as minimally invasive endoscopic resection instead of surgical resection. Evaluation of new devices and evolving techniques is important to consider. This needs to be balanced with the needs of the patients and population and evidence for their safety and clinical effectiveness, and cost-effectiveness relative to existing techniques. Clinical teams currently have limited resource, capacity, and time to test and evaluate new techniques, and so coordinated efforts to support the evaluation and integration of innovation is required.

Innovation involves a combination of national evidence synthesis, guidance and support, and local evaluation and feasibility of implementation. The national endoscopy programme's focus is on the development of fit for purpose, sustainable, and accredited services. Innovation in techniques is relevant to this agenda as for some patients, with certain requirements, new techniques may be superior or less resource intensive to deliver. The programme has considered a number of innovations such as colon capsule endoscopy and is working with a number of health boards to test the application of this technique. Allied national programmes, such as cancer, have also supported the testing of new techniques such as trans-nasal endoscopy. National organisations will continue to support national adoption of proven technologies.

Nonetheless, it is the responsibility of NHS organisations to determine which techniques and devices best deliver the requirements for their local populations, provided they comply with national standards of care.

Recommendation: In its response to this letter, the Welsh Government should provide further information on the wraparound care and support (including mental health support) available to people diagnosed with genetic conditions such as Lynch Syndrome in Wales. This should include information about how such care and support is tailored to the needs of particular groups, for example women of child-bearing age, people from ethnic minority communities, or disabled people.

The Welsh Health Specialised Services Committee (WHSSC) commissions Lynch testing as described in its Genomic Testing Policy Position PP184. This genomic test is commissioned from the All-Wales Medical Genomic Services (AWMGS). AWMGS is a single provider of genomic services for the population of Wales hosted by Cardiff and Vale University Health Board. Approximately 2,000 samples are received a year from all seven health boards. This has been a successful all-Wales implementation, ensuring patients in Wales can access recommended testing, equitably across Wales. We expect health boards to provide holistic and individualised care.

The AWMGS counsels and supports all people being tested for Lynch syndrome, both before testing, and afterwards if they are confirmed as having the condition. The service aims to support patients to understand their options and to decide how to proceed. This will take account of the individual circumstances of each person and includes any decisions that may need to be made about reproductive options, screening or surveillance, treatment, and chemoprevention.

I hope this information is helpful.

M. E. Myan

Yours Sincerely

Eluned Morgan AS/MS

Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Agenda Item 4.5

Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services



Russell George MS Chair, Health and Social Care Committee

SeneddHealth@senedd.wales

25 April 2023

Dear Russell

I am writing to inform the Committee of the UK Governments intent to make and lay the Healthcare (International Arrangements) (EU Exit) Regulations 2023 ("the HIA Regulations").

I have received a letter from Will Quince MP, Minister of State for Health and Secondary Care regarding the HIA Regulations, which the UK Government intends to lay in Spring 2023. UK Government officials have further advised that they are seeking to lay the Regulations in early June.

The HIA Regulations will extend to the whole UK. They will be made in exercise of powers conferred on the Secretary of State by the Healthcare (International Arrangements) Act 2019 ("the Act") (formerly titled the Healthcare (European Economic Area and Switzerland Arrangements) Act 2019 but to be renamed by section 162 of the Health and Care Act 2022). When section 162 is brought into force, it will commence the main enabling power for the HIA Regulations. The main enabling power will be contained in section 2 of the Act. Under section 2A of the Act, the Welsh Ministers may also make certain provision by regulations equivalent to that which the Secretary of State can make using section 2, although not all provision and only where the provision is within devolved competence.

The HIA Regulations will replace the UK legal framework for implementing healthcare arrangements provided for in existing regulations, the Healthcare (European Economic Area and Switzerland Arrangements) (EU Exit) Regulations 2019 ("HEEASA Regulations"), which are made in relation to the provision of reciprocal healthcare in EEA states and Switzerland, including the making of payments. The HEEASA Regulations also place duties on public authorities in Wales to give effect to reciprocal healthcare arrangements with the European Union (EU), European Economic Area Countries and Switzerland.

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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.

The HIA Regulations are to a large extent similar to the HEEASA Regulations, but broaden the scope of the legal framework to healthcare agreements between the UK Government and Rest of the World countries. The HIA Regulations:

- enable payments to be made pursuant to a reciprocal healthcare agreement by the Secretary of State on a UK wide basis;
- enable payments to be made by the Secretary of State in exceptional circumstances on a UK wide basis:
- impose a requirement to give effect to obligations and commitments of the UK under relevant healthcare agreements, including the processing of maternity planned treatment functions, on UK NHS Business Services Authority (NHS BSA);
- impose information and advice functions on NHS BSA;
- list Rest of World Countries party to international healthcare agreements with the UK;
- impose S2 planned treatment functions on NHS England, Welsh Local Health Boards and Scottish health boards (i.e. to carry out clinical determination of applications and to establish and publish procedures for the determination of S2 applications, which include provision for a review process).

Some aspects of the HIA Regulations could be made all or in part by provision contained in regulations made by the Welsh Ministers under section 2A of the Act.

Although the Welsh Government's general principle is that the law relating to devolved matters should be made and amended in Wales, on this occasion, I have considered it appropriate for the Secretary of State to legislate in relation to Wales.

The competence position in this area is complex. Whilst the Welsh Ministers have some power to make regulations in this area in relation to Wales, the legal framework in place for the provision of reciprocal healthcare is also intertwined with aspects outside of devolved competence. Therefore, separate UK Government and Wales-only regulations would be interdependent. As this area is so intertwined, I consider it prudent to have the legal framework in Wales established in one set of regulations, rather than split this between Wales only regulations and UK Regulations. This also makes the legislation more accessible, in line with good law principles.

The replacement legislative provision made by the HIA Regulations in relation to the UK's regime for reciprocal healthcare broadly retains the status quo under the current HEEASA Regulations. This means that provision which the Secretary of State would make in the HIA Regulations in relation to Wales and in devolved areas would be equivalent to the provision we would make in Wales only regulations. Therefore, having the UK Government make this provision for Wales would not be detrimental to the policy position in this area. This approach also does not preclude the Welsh Ministers from making Wales only regulations under section 2A of the Act in future.

Countries covered by International Healthcare Agreements are listed in a Schedule to the HIA Regulations. Given the UK Government is seeking agreements with a number of countries in the coming years and that each time countries are listed in the Schedule will need to be amended by affirmative procedure, I regard it as more pragmatic and efficient to have UK Government carry out this work on our behalf.

The approach within the HIA Regulations as drafted is not in conflict with either the Programme for Government or the Co-operation agreement.

These Regulations do not have implications for the Programme for Government.

I have written similarly to Huw Irranca-Davies MS, the Chair of the Legislation, Justice and Constitution Committee.

Yours sincerely

Eluned Morgan AS/MS

M. E. Myan

Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Y Pwyllgor lechyd a Gofal Cymdeithasol

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Health and Social Care Committee

Agenda Tem 4.6

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Peredur Owen Griffiths MS Chair Finance Committee

24 April 2023

Dear Peredur

Health boards: financial sustainability and balance

At our meeting on 30 March 2023, the Health and Social Care Committee considered the Welsh Government's response to our recent report on the Welsh Government's draft budget 2023-24. We have some ongoing concerns about health boards' financial performance, and would like to ask you to consider including financial scrutiny of health boards within your work programme.

We have considered health boards' financial positions during our scrutiny of the Welsh Government's draft budgets for 2022-23 and 2023-24, including the extent to which they are achieving their statutory responsibilities under the NHS Finances (Wales) Act 2014 i.e. their duties to manage their resources within approved limits over a three year rolling period; and to prepare, and have approved by Ministers, a rolling three-year Integrated Medium Term Plan. During oral evidence on the draft budget in each year we have discussed the situation with the Ministers, including how the Welsh Government is working with and supporting health boards.

However, we are concerned that our scrutiny of the 2023-24 draft budget suggests that health boards' financial positions have deteriorated rather than improved. The latest figures available to inform our scrutiny showed that, in aggregate, health boards were reporting an in-year deficit to date of £98.6m and a forecast end of year deficit of £159.9m for 2022-23. At that time, six out of the seven health boards were projecting end of year overspends. This is especially concerning as allocations to health boards represent a significant proportion of the overall Welsh Government budget each year.

In our report, we recommended that:

"The Welsh Government should provide further assurances about how it will ensure that all health boards in Wales achieve financial sustainability and balance within the 2023-24 to 2025-26 integrated medium term planning cycle. This should include clear timescales within which the Welsh Government anticipates each health board will achieve financial balance, and how progress will be monitored".

The Welsh Government accepted this recommendation in principle. In its <u>response</u>, the Welsh Government highlighted the "significant strain" on health board finances. It did not set out timescales for each health board to achieve financial balance, rather it noted that "most health boards" would not be able to present balanced integrated medium term plans in March 2023. It added:

"Work is required to scope, develop and implement opportunities for increasing efficiency and restoring financial stability and this will be taken forward in partnership between Welsh Government and senior NHS officials. Further updates will be provided to the Committee as this work progresses".

We are not yet assured that this will be sufficient given the deterioration we have seen and the ongoing pressures on our health services. We also have concerns about the level of Welsh Government capacity available to provide the support needed. We would be grateful, therefore, if you would consider including financial scrutiny of health boards within your work programme, including whether sufficient efforts are being made by health boards and the Welsh Government to regain health boards' financial sustainability and balance, and whether there is sufficient capacity available for this.

Yours sincerely

Russell George MS

Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.

Agenda Item 4.7

Y Pwyllgor Cyllid

Welsh Parliament

Finance Committee

Russell George MS

Chair, Health and Social Care Committee

2 May 2023

Dear Russell,

Scrutiny of Health Boards

Thank you for your letter dated 24 April.

I very much welcome you bringing these important issues to our attention. As recipients of substantial amounts of public funding, the robust scrutiny of health boards by the Senedd is essential to ensure value for money and appropriate use of public resources.

As you are aware, these are matters which the Finance Committee has considered previously, most recently through our scrutiny of the Welsh Government's Second Supplementary Budget 2022-23. Our report, published in March, made the following recommendation in relation to the financial performance of health boards, which will be of interest to your Committee:

"Recommendation 5. The Committee recommends that:

- measures are taken by the Welsh Government to ensure that each Local Health Board in Wales does not exceed its funding over the rolling three-year periods, as required by the National Health Service Finance (Wales) Act 2014; and
- where Local Health Boards are overspending in a single year, these should be funded from within the existing health and social services departmental budget."

In her <u>response</u>, the Minister for Finance and Local Government stated that:

"The National Health Service Finance (Wales) Act 2014 includes the responsibility for each Local Health Board to breakeven over a three-year accounting period and prepare plans to do so. The Minister for Health and Social Services and her officials regularly monitor performance against this



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duty and take escalation measures where necessary. Performance against this responsibility is reported as part of the audited accounts of each body.

Welsh Government's expectation is that wherever possible all MEGs meet any financial pressures arising in year, in the first instance, from within their existing budgets. Where this is not possible, or where other revisions are made to budgets, we will publish changes in line with our agreed process for supplementary budgets."

In addition to the strategic approach adopted by the Committee in relation to the scrutiny of the Welsh Government's budgetary proposals, it is a well-established principle that individual committees continue to scrutinise financial matters that fall within their remits.

This has worked effectively during the Sixth Senedd to date, enabling policy committees to delve into specific areas whilst allowing the Finance Committee to take a high level approach and consider the Welsh Government's budgetary proposals as a whole.

We will therefore continue to pursue issues of strategic importance such as these as part of our work programme, particularly during our scrutiny of the Welsh Government's Draft Budget and Supplementary Budget proposals. I trust you will also undertake scrutiny of health boards, as well as other key financial matters within your remit, when the time arises.

Yours sincerely

Peredur Owen Griffiths MS Chair of the Finance Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.



Agenda Item 7

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Agenda Item 8

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