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Agenda - Health and Social Care Committee

Meeting Venue:

Committee room 5, Tŷ Hywel and video conference via Zoom

Meeting date: 14 June 2023

Meeting time: 09.00

For further information contact:

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Private pre-meeting

(09.00-09.30)

1 Introductions, apologies, substitutions and declarations of interest

(09.30)

2 Gynaecological cancers: Panel 5 - Public Health Wales

(09.30-10.30) (Pages 1 - 21)

Professor Fu-Meng Khaw, National Director of Health Protection and Screening Services and Executive Medical Director, Public Health Wales

Dr Sharon Hillier, Director of the Screening Division, Public Health Wales

Research brief

Paper 1 Public Health Wales

3 Motion under Standing Order 17.42 (ix) to resolve to exclude the public for items 4, 5 and 8

4 NHS waiting times monitoring report

(10.30-10.40) (Pages 22 - 44)

Paper 2 - NHS Waiting times monitoring report

Senedd Cymru
Welsh Parliament

5 Dentistry: Welsh Government response

(10.40-10.50) (Pages 45 - 51)

Committee's report on dentistry

Welsh Government's response

Paper 3- Research Brief

Break

(10.50-11.05)

6 Gynaecological cancers: Panel 6

(11.05-12.05) (Pages 52 - 62)

Sadie Jones, Consultant Gynaecology Oncology Surgeon, Wales Cancer Research Centre

Professor Iolo Doull, All Wales Medicines Strategy Group

Andy Glyde, Cancer Research UK

Paper 4 - Cancer Research UK

7 Papers to note

(12.05)

7.1 Letter to the Royal College of Emergency Medicine regarding gynaecological cancers

(Pages 63 - 64)

7.2 Letter from the Royal College of Emergency Medicine regarding the inquiry into gynaecological cancers

(Pages 65 - 66)

7.3 Letter to the Minister for Social Justice from the Health and Social Care Committee and the Equality and Social Justice Committee regarding the accessibility of key public health information

(Pages 67 - 68)

7.4 Letter from the Minister for Social Justice to the Health and Social Care Committee and the Equality and Social Justice Committee regarding the accessibility of key public health information

(Pages 69 - 71)

7.5 Letter from Legislation, Justice, and Constitution Committee to Senedd Committees Chairs regarding UK Common Frameworks programme

(Page 72)

7.6 Letter from the Legislation, Justice, and Constitution Committee to the Minister for Health and Social Services regarding the Healthcare (International Arrangements) (EU Exit) Regulations 2023

(Pages 73 - 76)

7.7 Letter from the Minister for Health and Social Services to the Legislation, Justice, and Constitution Committee regarding the Healthcare (International Arrangements) (EU Exit) Regulations 2023

(Pages 77 - 90)

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

(Page 91)

7.9 Letter from the Deputy Minister for Mental Health and Wellbeing regarding the Fifth Senedd Health, Social Care and Sport Committee's inquiry into suicide prevention

(Pages 92 - 111)

7.10 Letter from the House of Lords Secondary Legislation Scrutiny Committee regarding the Health Service Procurement (Wales) Bill

(Page 112)

7.11 Letter to the Chief Nursing Officer for Wales regarding Nurse Staffing Levels (Wales) Act 2016: post-legislative scrutiny

(Pages 113 - 114)

7.12 Letter from the Nursing & Midwifery Council regarding the Department of Health and Social Care's consultation on, draft legislation for regulating anaesthesia associates and physician associates

(Pages 115 - 116)

7.13 Letter from RNIB Cymru regarding the Welsh Government's plan for transforming and modernising planned care

(Pages 117 - 122)

7.14 Letter from the Deputy Minister for Mental Health and Wellbeing regarding a healthier food environment in Wales

(Page 123)

8 Gynaecological cancers: consideration of evidence

(12.05-12.15)

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

Agenda Item 2

Document is Restricted

Health and Social Care Committee – inquiry into gynaecological cancers

Public Health Wales consultation response, March 2023

Public Health Wales is pleased to provide this written submission to the Health and Social Care Committee's consultation on gynaecological cancers.

Public Health Wales is the national public health agency in Wales and exists to protect and improve health and well-being and reduce health inequalities for people in Wales. We are one of the 11 organisations that make up NHS Wales.

1. Information and awareness of gynaecological cancers and screening

1.1 Information about risk factors and symptoms

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

Information about the risk factors for various gynaecological (and other) cancers in the community – specific to Wales, and compared to other UK countries and jurisdictions – has been published as a piece of collaborative research. The Welsh Cancer Intelligence and Surveillance (WCISU) at Public Health Wales was a major contributor to this UK-wide study and provided essential WCISU population-based cancer registry for Wales data, without which this comparative study would not have been possible. The study, *The fraction of cancer attributable to modifiable risk factors in England, Wales, Scotland Northern Ireland and the United Kingdom*, included risks for cancers of the vulva, vagina, cervix, ovary, and uterus. Summary findings are set out in Table 1 below.

Table 1: Summary findings of a study into the risk factors for gynaecological cancers

Vulva	• Protecting against certain infections (many strains of HPV) could prevent around 75% of vulval cancer cases every year in Wales (see section on HPV vaccination, below) • Incidence is higher amongst older age groups
Vagina	• Certain HPV infections contribute to 75% of cases. Protecting against such infections could prevent around 5 cases of vaginal cancer every year in Wales (see section on HPV vaccination, below) • Incidence is higher amongst older age groups
Cervix	• Certain infections (high-risk HPV) contribute to 99.8% of cases. • The majority of sexually active people will come into contact with high-risk HPV at some point in their lives. In most people their body's own immune system will deal with the virus. A minority of people who have a persistent high-risk HPV infection will develop cervical abnormalities, which could become cervical cancer if left untreated. • Protecting against these infections (vaccination) could prevent around 150 cases of cervical cancer every year in Wales • Tobacco smoking contributes to approximately 21% of cases. Not smoking could prevent around 35 cases of cervical cancer every year in Wales

	• Other risk factors include: having weakened immune system; longer-term use of oestrogen-progestogen oral contraceptive pills (risk reversible upon stopping and benefit outweigh risk); and not taking up cervical screening. • Incidence is higher amongst older age groups
Ovary	• Overweight and obesity contributes to about 7% of cases. Keeping a healthy weight could prevent around 20 cases of ovarian cancer every year in females in Wales • Post-menopausal hormones contribute to around 4% of ovarian cancer cases • Tobacco smoking contributes to less than 1% of cases. Not smoking could prevent less than 5 cases of ovarian cancer every year in Wales • Inherited conditions account for 5-15% of ovarian cancer cases; the majority of these hereditary cases are linked with BRCA1/2 mutations • Less than 1% of cases are contributed to by workplace exposures • Ovarian cancer risk is higher in current or recent users of oestrogen-only hormone replacement therapy (HRT), compared with never-users • Oestrogen-progestogen oral contraceptive use decreases the risk • Incidence is higher amongst older age groups
Uterus	• Around 34% of cases are contributed to by overweight and obesity. Keeping a healthy weight could prevent around 150 cases of uterine cancer every year in Wales • Hormone replacement therapy (HRT) (oestrogen-progestogen and oestrogen-only) is a risk factor • Physical inactivity is a risk factor • Oestrogen-progestogen contraceptives decrease risk • Incidence is higher amongst older age groups

In relation to public awareness of risk factors and symptoms of gynaecological cancers, we need to reflect carefully on the most appropriate approaches to this work. This would include a clear understanding of the risk factors that are amenable to individual action and the extent to which these are unique to cancer or gynaecological cancers.

It is very unlikely, based on the current available evidence, that gynaecological specific action on risk factors would be helpful or effective. The evidence outlined above (Table 1) suggests that age is the most consistent factor and that is not something which is modifiable. Increasing age is a risk factor for most cancers, the most appropriate action is to support the generic initiatives which encourage people to be aware of changes in their body and to seek help, ensuring that these specifically address the importance of age.

Other modifiable risk factors such as healthy weight, physical inactivity and smoking are in most cases responsible for a relatively small proportion of these cancers and secondly have an impact on a wide range of other disease outcomes. This is why we take a determinants-based approach to public health, that is focusing on the causes of the causes rather than a disease specific model. We need to increase the proportion of the population who are a healthy weight to prevent avoidable ill health and early death from a wide range of cancers, cardiovascular and liver diseases. Initiatives to increase understanding of the importance of healthy weight need to ensure they reflect this wide-ranging impact.

Public Health Wales has worked closely with Welsh Government, Directors of Public Health, and other partners to develop and implement strategic plans based on the best available international evidence of what works to address healthy weight (food and physical inactivity) and tobacco:

- *A smoke free Wales: Our long term tobacco control strategy*, sets out a vision for a smoke free Wales by 2030 (a prevalence of smoking in adults of 5% or lower).

- *The Healthy Weight Healthy Wales Strategy*, sets out our long-term plan to reverse the trend in rising levels of overweight and obesity. This is being delivered through a series of two year delivery plans focusing on Healthy Environments, Healthy Settings, Healthy People, and Leadership and Enabling Change.

Public Health Wales has previously supported NHS Wales-led awareness campaigns for cancer symptoms, and to not ignore symptoms, in partnership with third sector organisations. The WCISU in Public Health Wales also contributed to the evaluation of the 2016 lung cancer symptom awareness campaign. It found that symptom awareness, presentation, and GP-ordered chest X-rays increased during the campaign but this did not translate into increased urgent suspected cancer referrals or clinical outcomes changes.

For cervical cancer, Public Health Wales have developed information leaflets listing the symptoms and informing that need to contact their GP practice as soon as possible if they have concerns, rather than waiting for their next screening test. These leaflets are sent out with their invitation to screening letters.

1.2 Information about cervical cancer screening

Cervical Screening Wales is one of the seven population based screening programmes in Wales. The overall aim of Cervical Screening Wales is to reduce the incidence of morbidity and mortality from cervical cancer in Wales. The eligible population for cervical screening in Wales are women and people with a cervix aged between 25 and 64 years of age. Those eligible are contacted by letter and requested to book an appointment for a cervical screen (smear) test usually at their GP practice when they are due their next cervical screening test.

1.2.1 Changes to the Cervical Screening Wales programme

In January 2022, Public Health Wales announced changes to the Cervical Screening Wales programme in line with UK National Screening Committee recommendations and approved by the Welsh Government led Wales Screening Committee.

These changes came about as a result of improvements to the screening test that were implemented in September 2018. This is when Public Health Wales implemented Human papilloma virus (HPV) primary testing into the Cervical Screening Wales programme. Wales was the first UK nation to introduce this change. This test is more accurate and effective which means that, if no high-risk HPV is found, the time between appointments has increased from 3 years to 5 years. However, where HPV is found then participants are followed up more frequency and invited to screening in a year if no cell changes and if there are cell changes then referral made to colposcopy for review.

The announcement of these changes prompted misunderstanding amongst members of the public. As a result of the adverse reaction an internal After Action Review (AAR) was conducted on the 17 February 2022 with the aim to produce an agreed action plan which is followed through. Welsh Government also requested that a communications campaign was conducted to help explain the changes. Learning from the AAR was incorporated into the campaign.

The objective of the campaign was to rebuild trust in the safety and effectiveness of the cervical screening programme in Wales and to build understanding of HPV and HPV testing. The campaign was targeted primarily at women and people with a cervix aged 24-49 in Wales. A particular focus was given to reaching women in communities where screening uptake is generally lower, specifically: women living in areas with a high C2DE population; and women from Black, Asian and Minority Ethnic communities.

The campaign was a social media campaign as this was the channel where the negative feedback arose initially. All creative assets were developed by a creative agency using clear, plain language to enable immediate understanding and trust. Thorough testing of the messages/assets with the intended audience was undertaken to mitigate against any issues

around perception or misunderstandings. There was engagement with key partners such as Jo's Trust and Cancer Research UK to both inform the development of the creative assets and to ensure wider campaign reach.

A comprehensive communication plan was developed with detailed organic social media content, development and delivery of targeted social media ads and detailed stakeholder management plan. A PESTLE analysis which captured potential risks and mitigations of the campaign was undertaken before proceeding and a clear signoff process at team, divisional and directorate level was established.

60 Members of the Senedd received a letter to inform them about the campaign, its purpose and scope. Campaign materials and messaging were shared with Heads of communications at all seven health boards and Welsh Government's communications team.

An evaluation of the communication campaign which was run from 29 June to 22 August 2022 was undertaken and used the government communication service framework. In summary the campaign succeeded in:

- Developing a series of key messages shaped by four rounds of audience testing
- Achieving a combined reach of 173,215 across organic Facebook posts
- Gaining significantly more positive than negative reactions to organic Facebook posts. (Of the 455 reactions received, 327 were likes or loves.)
- Reaching 223,202 women aged 24-49 in Wales through Facebook and Instagram ads
- Reaching 149,900 women aged 24-49 in C2DE communities through Instagram and Facebook ads (99% of the estimated audience size of 150,800)
- Reaching 8,848 women aged 24-49 from Black, Asian and Minority Ethnic communities through Instagram and Facebook ads (98% of estimated audience size of 9,000)
- Achieving 103,200 impressions and 93,531 video views through TikTok ads

PHW made changes in response to several negative comments relating to use of ungendered language in a Twitter post to ensure all references were inclusive and referred to women and people with a cervix.

Key learning from the AAR that informed the approach to the reassurance campaign included:

- A risk assessment undertaken before starting the public campaign
- Engaged service users early, testing the key messages with four community groups that were representative of the target audiences
- Engaged key third sector stakeholders early, using insight and feedback from Cancer Research UK and Jo's Trust to shape the messaging
- Solicited feedback on campaign messaging and materials from other professional stakeholders, including the Welsh Government's communications team
- Contingency planning was undertaken in case there was a negative reaction
- Wider stakeholders were engaged with and the testing was undertaken in groups that were not already engaged in screening
- Used engagement expertise within PHW as part of stakeholder development

1.2.2 Supporting informed decision making

Cervical Screening Wales, like all screening programmes in Wales, aims to provide clear information about the screening being offered to allow those eligible to make an informed choice about whether they will participate or not. The programme sends out information leaflets to eligible participants to advise that their cervical screening test is due. All information for the public goes through a robust process of checking to ensure that it is clear, easy to read, and contains all the information necessary for them to make an informed choice.

The information covers harms and benefits and is balanced to allow participants to make their own personal informed decisions about taking part. The public information development process looks at how the information is presented as well as the content. User engagement is a key part of the process, including with specific community groups that would have different communication and information needs, to ensure that it is fit for purpose.

The information is available on the website in html to enable use with screen readers and other assistive technologies, and Easy Read versions have been developed in conjunction with Learning Disabilities Wales and ethnic minority community groups to ensure that the information is accessible for people with different levels of literacy. It is also available in British Sign Language and audio as standard, with a translation service on the website and other formats available on request.

1.3 Barriers to diagnosis

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.

Ensuring that health professionals understand the attributable risk of different factors in the development of cancer is important in supporting them to make evidence informed decisions when patients present with symptoms. The work of the WCISU outlined above (section 1.1) supports this process. WCISU is collaborating with many NHS, university and third sector partners, along with the Royal College of General Practitioners, in a National Cancer Diagnosis Audit in Wales (and elsewhere in the UK) which examines the patient pathway in primary care in relation to symptoms. This includes and disaggregates information relating to gynaecological cancer cases in Wales.

The Wales Cancer Patient Experience Survey, led by the Wales Cancer Network, supported and contributed to by WCISU (which also holds the data of several surveys) provides more information on how people experience the process of cancer diagnosis and treatment. The latest data was collected in 2021, and can be filtered to view data on gynaecological cancers. The survey collects information on the number of times people saw their GP before they were told they needed to go to hospital about cancer, and how they felt about how long it took to get their first hospital appointment. The data dashboard can be found here.

Public Health Wales' WCISU continues to be heavily involved in a range of international research that provides comparisons and insights into the causes and factors contributing to delayed diagnosis. One of the most important is the International Cancer Benchmarking Partnership (ICBP). Phase 1 of the Partnership's research examined the following for ovarian cancers (amongst several other non-gynaecological cancers):

- Public awareness, beliefs and attitudes to cancer
- The role of primary care practitioners in diagnosing cancer
- Measuring time intervals from diagnosis to treatment
- Exploring factors that may impact short term survival

A summary of the ICBP Phase 1 findings, which compares Wales to the other participating countries and jurisdictions, can be found here.

The more recent phase 2 of the ICBP also included Wales and considerable input from WCISU. Ovarian cancer was included. The areas explored included:

- Access to diagnostics and investigations
- Access to optimal treatment
- Structure of health systems
- Cancer care pathways

A summary of the ICBP Phase 2 findings which compares Wales to the other participating countries and jurisdictions can be found here.

PHW's WCISU collaborates with the Wales Cancer Network and participates in the Wales Cancer Board and its various sub-groups to disseminate the above findings and assist data and evidence-based decision-making.

1.4 Data collection

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.

1.4.1 Incidence, prevalence, and survival data

Each year, the official statistics for Wales – based on the whole population cancer registry data compiled by WCISU – disaggregate gynaecological cancer by the main cancer types and currently by age and area deprivation. In summary, for example:

Table 2: 2019 cancer incidence Wales

	Annual count of cases	Age-standardised rate per 100,000
Uterus	530	30.4
Ovary	306	17.9
Cervix	145	9.5

Table 3: 2019 cancer mortality Wales

	Annual count of cases	Age-standardised rate per 100,000
Uterus	136	7.4
Ovary	2020	12.3
Cervix	43	3.5

Table 4: One-year net survival (%) for women diagnosed 2015-2019

Uterus	89.54
Ovary	72.10
Cervix	81.14

Further detailed official statistics of cancer in Wales – including gynaecological cancer – by Public Health Wales's WCISU can be found here.

In addition, Public Health Wales's WCISU has estimated the prevalence of people living with cancer who had had a diagnosis in the past. This included a breakdown by cancer type (including for ovarian and uterine cancers), by age/sex, by area deprivation, by rural/urban areas, by geography (Wales, health boards, GP clusters). The information dashboard can be found here.

Public Health Wales' WCISU continues to be heavily involved in a range of international research that provides comparisons and insights into comparative cancer epidemiology. Phase 1 of the International Cancer Benchmarking Partnership (ICBP) examined the incidence of ovarian cancer (amongst several other non-gynaecological cancers). A summary of the ICBP Phase 1 findings which compares Wales to the other participating countries and jurisdictions can be found here.

A summary of the more recent ICBP Phase 2 findings which compared the incidence and survival of several cancers including ovarian cancer in Wales to the other participating countries and jurisdictions can be found here.

1.4.2 Screening uptake data

Currently cervical screening coverage data is disaggregated by age and deprivation status. No other protected characteristics are recorded on the CSW database so we are unable to analyse coverage by ethnicity. PHW also report coverage by geographical area (published at Wales, Health Board, Local Authority and GP cluster level). This can be viewed here.

As part of Public Health Wales's Screening Equity Strategy, we have committed to publishing an annual equity report to enable access to meaningful data that can inform action. The latest published version is available here.

We are also working on developing a sustainable approach to monitoring uptake by minority ethnic communities and other under-served groups, supporting local and national approaches to improve data collection. We are exploring different ways of getting the data we need including linkage through the SAIL databank in Swansea University and exploring with Digital Health and Care Wales what data we can get from primary care systems.

1.4.3 Future priorities

Public Health Wales is leading a data sub-group of the new NHS Health Inequalities Group. The data sub-group is responsible for:

- conducting a gap analysis of health data sets (including screening and cancer) and reporting on the gaps;
- developing proposals for data-driven approaches the NHS can take with the greatest impact on tackling health inequalities; and
- identifying relevant metrics.

We look forward to working with others to help address these issues and will note relevant recommendations on future data collection that may come from this inquiry and other potential opportunities for example Census data.

2. Recovery of gynaecological cancer services post COVID-19

2.1 Cervical screening services

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.
Access to timely screening services including consideration of the inequalities and barriers that exist in uptake among different groups of women and girls.

Following the temporary pause in sending screening invitation for 3 months due to the covid pandemic (March to May 2020), the programme was fully recovered the delay from December 2021. When the invitations were restarted in June 2020 a risk-based approach was taken with participants on early repeat being invited as priority. Additional routine recall participants were invited monthly in a phased and measured approach agreed with General Practitioners Committee Wales until full recovery was achieved. Colposcopy services across Wales continued to see participants referred throughout the pandemic.

Looking ahead, Public Health Wales's WCISU has provided population-based cancer registry data to Cancer Research UK and collaborated on crude projection estimates of cancers in 2040, found here. Public Health Wales's WCISU and Data Science team are exploring methods of more accurate projections and predictions for a variety of cancer types, including gynaecological cancers, based on the effects of the COVID-19 pandemic and variations in risk factor prevalence in the population. This intelligence can be used to inform, among other things, cervical cancer screening capacity requirements.

2.1.1 Self-sampling

Public Health Wales provides information and support to help people eligible for cervical screening to make an informed decisions about their participation (see section 1.2.2). Nearly 7 out of 10 women invited for screening take up their offer.

Addressing barriers to taking up screening offer to improve uptake and reduce inequity is a key focus for the programme. Self-sampling is potentially an intervention that will address identified barriers such as embarrassment. Self-sampling is where a person can takes a self-collected vaginal sample, in their own home, rather than going to screening appointment where the cervical screening test is undertaken by a healthcare professional. This self-sample can then be sent to the laboratory to be tested for high-risk HPV virus.

There are, however, a number of potential concerns, which include:

- the rigour applied to research and evaluation of self-sampling studies previously conducted;
- the sensitivity and specificity of self-sampling is lower than the clinician taken samples;
- if individuals who have previously been regular attenders for the clinician taken samples test switch to self-sampling this would potentially result in less screen detected high-grade cervical intraepithelial neoplasia (cervical cancer); and
- early indications from countries that have introduced self-testing are that uptake has not increased in individuals who have not participated in clinician taken cervical screening.

A validation study called HPValidate is currently underway in England. Three self-sample devices are undergoing clinical validation in England on two HPV primary screening platforms across five laboratories. This work was due to conclude in December 2023.

In-service evaluation of self-sampling to explore how offering self-sampling could maintain or improve the screening programme and explore feasibility and acceptability in planned in England. Cervical Screening Wales is hoping to be involved with this work.

Recommendations from the UK NSC on self-sampling will be considered by the Wales Screening Committee when available and Cervical Screening Wales will be guided by the outcome of these to inform any changes to the programme for improvement.

2.1.2 Improving equity of access

As part of the post-COVID recovery work at Public Health Wales, the screening division has developed an Equity Strategy. Our vision, across the national screening programmes in Wales, is that everyone eligible for screening has equitable access and opportunity to take up their screening offer using reliable information to make a personal informed choice. The purpose of the strategy is to identify how, through collaborative working with our partners in Local Health Boards, the third sector, and the people of Wales we can achieve this ambition. The strategy identifies a series of commitments to progress actions across five key areas: Communication, Community and engagement, Collaboration, Service Delivery and Data and Monitoring.

2.2 HPV vaccination programme

HPV vaccination including consideration of the inequalities and barriers that exist in uptake among different groups of women and girls.

HPV vaccination plays a vital role in gynaecological cancer prevention. Public Health Wales support Welsh Government and NHS Wales with scientific evidence, clinical advice, and epidemiological intelligence to support vaccine policy development and vaccine delivery. Delivery of HPV vaccines in Wales is commissioned by local health boards and in the most part

delivered in schools by school nursing teams. HPV vaccination is then available for all girls and boys via GPs until the age of 25 (although it is most effective when given before commencement of regular sexual activity). For men who have sex with men, and others who are at similarly higher risk and attending sexual health services, or HIV clinics, the vaccine is available up to 45 years of age.

Previously the HPV vaccination programme was only available to girls but from 2021-21, boys have been added to the programme. HPV vaccination is effective at preventing a range of anal, penile and oropharyngeal cancers that can directly benefit all children and can also indirectly reduce exposure of girls to the virus.

Due to the HPV vaccination programme changing during the COVID19 pandemic to include all children, pre-COVID-19 data (2019/20) only includes vaccination uptake by girls, whereas the post-COVID data (2021/22) relates to uptake by all children (see Table 1). The apparent drop in HPV uptake is predominantly due to lower uptake in boys, while uptake by girls has remained at a similar level pre-and post-COVID-19.

Table 5: HPV uptake from the COVER annual report for 2019-20 and 2021-22

	Dose 1 by 1st April in Girls School Year 9 (2019-20 academic year)	Dose 1 by 1st April in Children School Year 9 (2021-22 academic year)
Wales	87.3%	78.9%
Regional (LHB) variation	81.4%-94.7%	73.8%-91.1%

There is, however, significant regional variation in vaccination uptake, and the uptake in most areas falls short of the WHO target of 90% uptake for the elimination of cervical cancer, so there is much still to be done.

Table 2 below summarises the most recent data published for England and Scotland that is most equivalent to Wales data. It shows that uptake in Wales is broadly comparable to England and Scotland for equivalent age cohorts.

Table 6: Uptake by 31 Aug 2022 (30 Sep in Wales) for the last complete school year

	Uptake of dose 1 in girls by end of yr 8	Uptake of dose 1 in girls by end of yr 9	Uptake of dose 2 in girls by end of yr 9
England (regional variation)	69.6% (61.6%-74.9%)	82.2% (74.0%-85.7%)	67.3% (60.0%-75.1%)
Scotland (regional variation)	77.5% (68.9%-85.2%)	86.4% (80.2%-89.9%)	64.8% (23.2%-77.0%)
Wales (regional variation)	70.0% (51.0%-87.4%)	84.7% (80.0%-91.1%)	70.6% (54.5%-81.5%)

The Joint Committee on Vaccination and Immunisation has advised that from the next academic year (Sep 2023) the HPV programme should be reduced to a single dose, rather than two. This provides an important opportunity to promote HPV vaccination in all children. Public Health Wales is aiming to achieve vaccine uptake of over 90% by all children, in line with WHO guidelines, and to reduce inequalities that currently exist. For example, we see lower uptake in children who are home schooled or are from more deprived areas or ethnic minority communities.

Public Health Wales Vaccine Preventable Disease Programme are actively working to evaluate equality of HPV vaccine uptake through data linkage. We are also working with schools and

school nursing teams, with children and other stakeholders to better understand the barriers to vaccination and how we can support the increases in uptake we would like to see. To support school nursing teams in monitoring coverage in their schools, we have developing vaccine uptake surveillance reports at school level, alongside the suite of vaccine coverage surveillance reports already available. We are working with colleagues in screening and The Welsh Cancer Intelligence & Surveillance Unit to set up a long-term programme of work to evaluate and monitor HPV vaccine effectiveness, and are undertaking collaborative work to identify those at most risk of not having HPV vaccination or taking part in cervical screening. These women are at highest risk of cervical cancer in the future, so identifying how we can work together to remove barriers will be critical.

2.3 Waiting times

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).

PHW are currently exploring waiting list data, in response to the Minister for Health and Social Service's request to target people on waiting lists for health behaviour related interventions and to analyse waiting lists in relation to excess deaths. We will assess the quality of data available for assessment by geography and protected characteristics.

Public Health Wales's WCISU and Observatory Cancer Analysis Team have collaborated in providing near-real time monthly cancer incidence data based on pathology-confirmed new cases of cancer 2020-2022. Currently, this is only available on Public Health Wales's intranet. Next steps for this work include:

- Continue updating the data monthly through 2023 and beyond
- Break down by further cancer types: including some gynaecological cancers
- Make it available publically on the internet

This will give an indication of gynaecological (and other) cancers being diagnosed using definitive pathology/cytology sample assessment (rather than clinically or radiologically alone) before, during and subsequent to the height of the COVID-19 pandemic.

3. Innovation in prevention and early intervention in cancer care

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.
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.

As stated in section 1.1, Public Health Wales works closely with Welsh Government and others to address risk factors for cancer, including gynaecological cancers, such as promoting healthy weight and smoking cessation. For cervical cancer, HPV vaccination and regular screening are the priorities for prevention. Public Health Wales continues to lead this work and undertake research to support innovation (section 2.1).

More broadly, the research agenda for cancer is coordinated by Health Care Research Wales's Wales Cancer Research Centre, who are implementing and overseeing the new Wales Cancer Research Strategy, launched in 2022.

Public Health Wales's WCISU is involved in cancer genome data research and will imminently be receiving cancer tumour molecular data (genetic/receptor markers) for all residents of Wales diagnosed with cancer, and who receive a test either in a Welsh or English hospital. This would also include anyone with a gynaecological cancer that is tested for molecular markers. Furthermore, WCISU is participating in a collaborative project with the cancer registry in England on collecting information about cancer susceptibility genes such as BRCA1/2, important for some gynaecological cancers. This whole population data will also be available in due course for research and data linkage with appropriate safeguards and information governance.

Response prepared by:

- Christopher Johnson, Head of Vaccine Preventable Diseases Programme
- Dyfed Wyn Huws, Consultant in Public Health Medicine and Director of the Welsh Cancer Intelligence and Surveillance Unit
- Heather Lewis, Consultant in Public Health, Screening
- Julie Bishop, Director of Health Improvement
- Lisa Henry, Head of Programme – Cervical Screening Wales
- Meng Khaw, National Director of Screening and Health Protection Services
- Nathan Lester, Head of Observatory Analytical Team
- Sharon Hillier, Director Screening Division
- Sikha de Souza, Consultant in Public Health, Screening
- Simon Cottrell, Senior Principal Epidemiologist
- Louisa Petchey, Senior Policy Specialist

Agenda Item 4

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

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Agenda Item 5

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Agenda Item 6

Health and Social Care Committee inquiry into gynaecological cancers
Cancer Research UK Response – January 2023

Introduction and recommendations

Cancer Research UK welcomes the opportunity to respond to the Health and Social Care Committee's consultation on gynaecological cancers, and the spotlight this inquiry will give to gynaecological cancers in Wales.

Each year, around 1,200 people are diagnosed with gynaecological cancer in Wales.[1] The incidence rate for gynaecological cancer is significantly higher in Wales (72 cases per 100,000 female population) compared to the UK average (68 cases per 100,000 female population).[2]

Each year, around 470 people die from gynaecological cancer in Wales.[3] The mortality rate for gynaecological cancer is significantly higher in Wales (26 deaths per 100,000 female population) compared to the UK average (24 deaths per 100,000 female population).[4]

In addition, there is some evidence from the International Cancer Benchmarking Partnership (ICBP) to suggest that ovarian cancer patients in Wales do have longer patient intervals and primary care intervals compared to countries with higher survival such as Denmark[5].

Our submission highlights important issues regarding awareness and symptom knowledge of gynaecological cancers, access to primary care and long waits for diagnostic tests and treatment for some cancers. We also look at the HPV vaccination programme, where improvements can be made, and where there is opportunity for innovations in the gynaecological cancer space.

Recommendations for Welsh Government, the Wales Cancer Network and Public Health Wales to consider:

- Explore innovative approaches to communicate information about risk and symptoms for gynaecological cancers, including targeted and tailored activity to remove barriers to help-seeking including increasing awareness and widening access to health care.
- Improve access to training and education for healthcare professionals in primary care.
- Consider options for allowing patients to self-refer with gynaecological cancer symptoms.
- Vaccination teams across Wales should continue to deliver the HPV vaccination programme, ensuring hard to reach groups are positively engaged. Focus needs to be put on areas and groups with lower uptake to strengthen programme delivery, increase uptake rates and reduce inequalities.
- Report diagnostic waiting list data for gynaecological cancers routinely, broken down by cancer type, region and other relevant factors to ensure transparency and support identification of challenges in the system.

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[1] Based on the average number of new cases of gynaecological cancer (ICD10 C51-58) diagnosed in Wales in the years 2016-2018.

[2] Based on the average annual European age-standardised incidence rate per 100,000 female population for gynaecological cancer (ICD10 C51-C58) in Wales in the years 2016-2018.

[3] Based on the average annual number of deaths from gynaecological cancer (ICD10 C51-C58) in Wales in the years 2017-2019.

[4] Based on the average annual European age-standardised mortality rate per 100,000 female population for gynaecological cancer (ICD10 C51-C58) in Wales in the years 2017-2019.

[5] Menon, U., Weller, D., Falborg, A.Z. et al. Diagnostic routes and time intervals for ovarian cancer in nine international jurisdictions; findings from the International Cancer Benchmarking Partnership (ICBP). Br J Cancer 127, 844–854 (2022). https://doi.org/10.1038/s41416-022-01844-0

- Data reported for gynaecological cancers should be disaggregated, to provide information on service provision, helping to understand how well services are performing generally and for specific groups of patients, whether that's people with different types of cancer or different sociodemographic characteristics.

Welsh Government has an opportunity to address wider challenges facing cancer services in Wales in its forthcoming NHS Cancer Services Action Plan, in particular:

- Funding: the strategy must be backed up with significant funding to help ensure it delivers the meaningful improvements people affected by cancer deserve, as well as gain the confidence of the cancer community and wider public. Investment is needed to improve patient outcomes and unlock the benefits of innovative approaches and increased efficiency.
- Action on workforce: the Welsh Government must set out long-term plans to deliver a sustained expansion of the cancer workforce to meet future demand for cancer services and tackle the chronic shortages in the workforce specialities key to diagnosing and treating cancer. This must be matched with sufficient and sustainable capital funding to ensure diagnostic and treatment capacity is meaningfully expanded across Wales.
- Better use of data: data is fundamental to driving our progress against cancer. The Welsh Government should prioritise making improvements in the collection and reporting of datasets to unlock better intelligence and data-driven action in the years to come.

The NHS Cancer Services Action Plan is due be published in early 2023. Whilst the Plan won't be long-term – we understand it will be for 2023-2026 - it has the potential to be a major milestone for people affected by cancer in Wales, signalling a renewed drive and setting an ambitious roadmap towards better cancer outcomes.

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

We are not aware of recent evidence looking at awareness of risk factors and symptoms associated with gynaecological cancers specifically in Wales. Older UK and international studies suggest that awareness of symptoms associated with ovarian cancer is low[6,7]. More recently, a Target Ovarian Cancer report suggests that awareness of some ovarian cancer symptoms is low amongst women in the UK and that some women wrongly believe that cervical screening detects ovarian cancer[8].

To address this, innovative approaches to communicating information about risk and symptoms should be considered, including, where supported by evidence, targeted and tailored activity to remove barriers to help-seeking including increasing awareness and widening access to health care. This might include identification of opportunities to share

[6] Brain KE, Smits S, Simon AE, Forbes LJ, Roberts C, Robbé IJ, Steward J, White C, Neal RD, Hanson J; ICBP Module 2 Working Group. Ovarian cancer symptom awareness and anticipated delayed presentation in a population sample. BMC Cancer. 2014 Mar 10;14:171. doi: 10.1186/1471-2407-14-171.

[7] Low EL, Waller J, Menon U, Jones A, Reid F, Simon AE. Ovarian cancer symptom awareness and anticipated time to help-seeking for symptoms among UK women. J Fam Plann Reprod Health Care. 2013 Jul;39(3):163-71. doi: 10.1136/jfprhc-2012-100473.

[8] Target Ovarian Cancer. Pathfinder 2022: Faster, Further and Fairer. Accessed December 2022. https://targetovariancancer.org.uk/news/progress-possible-if-urgent-action-taken-now-our-new-research-reveals

information about cancer risk and symptoms. For example, as part of the Cancer Loyalty Card Study (CLOCS)[9], researchers are hoping to understand more about public preferences on communication of early signs of ovarian cancer using loyalty card data which may inform recommendations on using supermarket messaging on cancer risk and symptoms. This study is also looking at changes in purchases of relevant items e.g. pain killers and indigestion medication prior to ovarian cancer diagnosis. This study commenced in 2019 and to our knowledge, ended in July 2022 – so we expect results to be published soon. The previous proof of concept study found a unique presence of purchases for pain and indigestion medication prior to ovarian cancer diagnosis, which could signal disease in a larger sample[10].

The barriers to securing a diagnosis, such as symptoms being dismissed or confused with other conditions.

There are various barriers to securing a gynaecological cancer diagnosis including:

- Low awareness of risk factors and symptoms associated with gynaecological cancer and difficulties in accessing primary care[11]
- Non-specific symptoms which may be attributed to something else. While some gynaecological cancer symptoms are more specific e.g. abnormal bleeding in endometrial, cervical and vaginal cancers, symptoms of ovarian cancer can be very vague and include abdominal pain, appetite loss, bloating and needing to urinate more often. Evidence suggests these non-specific symptoms have low predictive value for ovarian cancer in primary care.[12]
- (Particularly during the pandemic period), people not wanting to seek help due to concerns about COVID-19 or not wanting to burden the health service[13]

This can result in it taking longer for someone to seek help (patient interval) and/or longer for someone to be referred by their GP (primary care interval). There is some evidence from the International Cancer Benchmarking Partnership (ICBP) to suggest that ovarian cancer patients in Wales do have longer patient intervals and primary care intervals compared to countries with higher survival such as Denmark[14]. Patient intervals and primary care intervals were longer in Wales compared to Denmark (31 days vs 12 days, and 8 days vs 1 day, respectively). This suggests there is scope for improvement in terms of public awareness, help-seeking, access to primary care, access to training and education for healthcare professionals in primary care and timely referrals to secondary care in Wales.

Accessing primary care

[9] Brewer HR, Hirst Y, Sundar S, et al. Cancer Loyalty Card Study (CLOCS): protocol for an observational case–control study focusing on the patient interval in ovarian cancer diagnosis. BMJ Open 2020;10:e037459. doi: 10.1136/bmjopen-2020-037459

[10] Flanagan JM, Skrobanski H, Shi X, Hirst Y. Self-Care Behaviors of Ovarian Cancer Patients Before Their Diagnosis: Proof-of-Concept Study. JMIR Cancer. 2019 Jan 17;5(1):e10447. doi: 10.2196/10447.

[11] Pauline Williams, Marie-Claire Rebeiz, Leila Hojeij, Stephen J McCall. British Journal of General Practice 2022; 72 (725): e849-e856. DOI: 10.3399/BJGP.2022.0071

[12] Hamilton W, Peters T J, Bankhead C, Sharp D. Risk of ovarian cancer in women with symptoms in primary care: population based case-control study BMJ 2009; 339 :b2998 doi:10.1136/bmj.b2998

[13] Quinn-Scoggins HD, Cannings-John R, Moriarty Y, et al. Cancer symptom experience and helpseeking behaviour during the COVID-19 pandemic in the UK: a cross-sectional population survey. BMJ Open 2021;11:e053095. doi:10.1136/ bmjopen-2021-053095

[14] Menon, U., Weller, D., Falborg, A.Z. et al. Diagnostic routes and time intervals for ovarian cancer in nine international jurisdictions; findings from the International Cancer Benchmarking Partnership (ICBP). Br J Cancer 127, 844–854 (2022). https://doi.org/10.1038/s41416-022-01844-0

The difficulties in getting an appointment in primary care are well documented, highlighting significant capacity issues in health services that need to be addressed. Other nations in the UK are considering different interventions to widen access including self-referral routes, pharmacy referrals and remote consultations. It is important that the opportunity for innovation in this space is also considered in Wales, sharing with, and learning from other UK nations where appropriate, and ensuring steps are taken to mitigate against the risk of widening health inequalities for those less likely to engage with particular routes.

Self-referral

There may also be a role for a self-referral pathway, that is a pathway where people can refer themselves for diagnostic tests without seeing their GP, to support people experiencing possible gynaecological cancer symptoms to access timely further investigation. Some cancer pathways will be more amenable than others; those cancers with red flag symptoms, such as postmenopausal bleeding in some gynaecological cancers, and higher levels of symptom awareness are likely to benefit most. There are different possible approaches to self-referral including symptom awareness campaigns that direct people with certain symptoms to a cancer 'hotline' or to book a test.

Preference for self-referral may vary between different patient groups, and people who are more deprived and younger may be less likely to self-refer. It will be important to consider possible barriers to self-referral for some people and ensure it does not cause inequalities in the diagnosis of gynaecological cancers.

It will also be essential to ensure primary care health-professionals are involved in the development of any self-referral pilots, and areas are alerted to their presence in case questions/issues emerge. We asked GPs in Wales (n=45) whether they think self-referral could be an option for various cancer sites and signs or symptoms[15]. For endometrial cancer, most GPs (78%) reported that self-referral could be an option for people with post-menopausal bleeding or discharge. For cervical cancer, less than half (42%) of GPs reported that self-referral could be an option for people with abnormal vaginal bleeding or discharge.

In a public poll, we asked people how likely or unlikely they would be to consider a self-referral route rather than go to a test following an appointment. Just over two-thirds of the people were likely to self-refer for specialist tests or appointments. Around 1 in 5 people were not likely to self-refer and further research is needed to explore their reasons. Variation was observed across different groups:

- Older people (55+) were more likely to have said they would self-refer compared to all the younger age groups
- Women are more likely to have said they would net likely self-refer when compared to men for both specialist tests and appointments.
- People from the C2DE less likely to have said they would self-refer when compared to those from the ABC1 for both specialist tests and appointments

Pharmacy

Referrals into primary and secondary care by pharmacists are also of interest. As highly trained health professionals situated in the community closer to people's homes, it is hoped that pharmacists are well placed to spot potential signs and symptoms and will be able to facilitate early cancer diagnosis by directly referring people to primary or secondary care. Pharmacy

[15] Cancer Research UK GP Omnibus survey (2022) Unpublished findings. Data collected by medeConnect who interview 1000 regionally representative UK GPs online. medeConnect is a division of Doctors.net.uk'

referral pilots are at early stages and robust evaluation is required to answer questions about how this would work in practice, the receptiveness of the public and health professionals, and crucially, to understand the effectiveness of pharmacy referrals with regards to cancer diagnoses, the impact on non-cancer diagnoses and any positive or negative impacts on health inequalities.

Supporting recognition of potential cancer in primary care

The majority of all cancer patients present symptomatically, and via primary care. Therefore supporting primary care in timely recognition and referral of suspected cancer is crucial.

While our understanding is that awareness and use of the NICE guideline to support recognition and referral of cancer in primary care is good in Wales, new evidence has emerged since this was last updated, including for gynaecological signs and symptoms. In particular, for ovarian cancer, new evidence on the blood test CA125 is available which may support the use of age-specific thresholds for using this test, as well as parallel testing of CA125 with ultrasound. CA125 and ultrasound are tests that can be used in the diagnosis of ovarian cancer and new evidence around their use is already reflected in the Scottish referral guidelines for suspected cancer. This should be part of a wider review of this guidance alongside new evidence on vague symptoms, many of which are associated with gynaecological cancers, gleaned from activity in rapid diagnostic centres (RDCs).

The Wales Interventions and Cancer Knowledge about Early Diagnosis (WICKED) research programme is aiming to improve the quality and consistency of primary care approaches in order to improve timely diagnosis of cancer. This programme has developed an intervention to change primary care health professionals' knowledge, attitudes and clinical behaviour with the intention of reducing primary care intervals and improving cancer outcomes. This intervention – ThinkCancer! – involves session for clinical and non-clinical staff, creation of a practice-specific Cancer Safety Netting Plan (CSNP) and the appointment of a Cancer Safety Netting Champion (CSNC) to lead on implementation of the CSNP. Following a recent successful feasibility study, this intervention will be evaluated in a phase randomised controlled trial involving GP practices from across Wales and the North West of England[16].

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.

A result of years of research carried out across the world, including in Wales, the development and introduction of human papillomavirus (HPV) vaccination to reduce cervical cancer rates has undoubtedly been a success. In the first study of its kind funded by Cancer Research UK, the bivalent Cervarix HPV vaccine was shown to dramatically reduce cervical cancer rates by 87% in women in their 20s who were offered it at age 12 to 13 in England[17].

Across the UK, the HPV vaccination programme has been disrupted due to school closures during the pandemic, and data on HPV vaccination in Wales from 2021/22 suggests vaccine uptake is not back to pre-pandemic levels. Uptake of dose 1 in year 9 females was 82.1% in

[16] http://wicked.bangor.ac.uk/

[17] Falcaro, M et al. The effects of the national HPV vaccination programme in England, UK, on cervical cancer and grade 3 cervical intraepithelial neoplasia incidence: a register-based observational study. Lancet. 2021;398(10316):2084-2092.

2021/22[18] compared to 87.3% in 2019/20[19]. Uptake of dose 2 was also lower in 2021/22 across monitored age groups. Uptake also ranged across Health Board/Local Authority. Unfortunately, Wales do not collect and/or report data on HPV vaccination and ethnicity/deprivation. However, some research suggests that uptake of vaccination in the catch-up cohort was lower in women living in more deprived areas in Wales[20]. Uptake of cervical screening was also lower in this group.

Vaccination teams across Wales should continue to deliver the HPV vaccination programme, ensuring hard to reach groups are positively engaged. Particular focus needs to be put on areas and groups with lower uptake to strengthen programme delivery, increase uptake rates and reduce inequalities. To facilitate this, data on uptake by deprivation quintile and wherever possible, ethnicity should be collected and reported on.

The Screening Division Inequities Report 2020-21 (Screening Division of Public Health Wales) reports that cervical cancer screening coverage is now just below the minimum service standard of coverage (70%), at 69.5% (as of October 2021)[21]. This is a decline from 73.2% reported in 2019/20. There is geographical variation in coverage across Health Boards, the lowest in Hywel Dda University Health Board at 67.7% and highest in Powys Teaching Health Board at 72.7%. Further, coverage was highest in the least deprived areas at 75.4% and lowest in the most deprived areas at 63.3%, a trend observed across all Health Boards. In terms of age, coverage is lowest in the youngest age group (25-29 years) across Wales, at 63.4%; the trend for lower uptake in younger age groups is seen across all Health Boards.

Evidence on existing inequalities in cervical cancer screening coverage in Wales suggest the need to target support in accessing screening services at certain groups, particularly younger people (25-29 years) and those living in the most deprived areas. Therefore, we support the cervical screening recommendations within the Women's Health Quality Statement for:

- Co-production and implementation of targeted interventions to engage with women who are in those demographics least likely to attend cervical screening or access sexual and reproductive services.
- Work underway to increase uptake of cervical screening and follow-up procedures to ensure the effectiveness of the cervical screening programme, saving as many lives as possible from cervical cancer.
- Information and signposting to sources of support following diagnosis of cell-changes after cervical screening.

[18] Public Health Wales. 2022. Vaccine Uptake in Children in Wales COVER Annual Report 2022. Accessed December 2022 via https://phw.nhs.wales/topics/immunisation-and-vaccines/cover-national-childhood-immunisation-uptake-data/cover-archive-folder/annual-reports/vaccine-uptake-in-children-in-wales-cover-annual-report-2022/

[19] Public Health Wales. 2020. Vaccine Uptake in Children in Wales COVER Annual Report 2020. Accessed December 2022 via https://phw.nhs.wales/topics/immunisation-and-vaccines/cover-national-childhood-immunisation-uptake-data/cover-archive-folder/annual-reports/vaccine-uptake-in-children-in-wales-cover-annual-report-2020/

[20] Beer H, Hibbitts S, Brophy S, Rahman MA, Waller J, Paranjothy S. Does the HPV vaccination programme have implications for cervical screening programmes in the UK? Vaccine. 2014 Apr 1;32(16):1828-33. doi: 10.1016/j.vaccine.2014.01.087

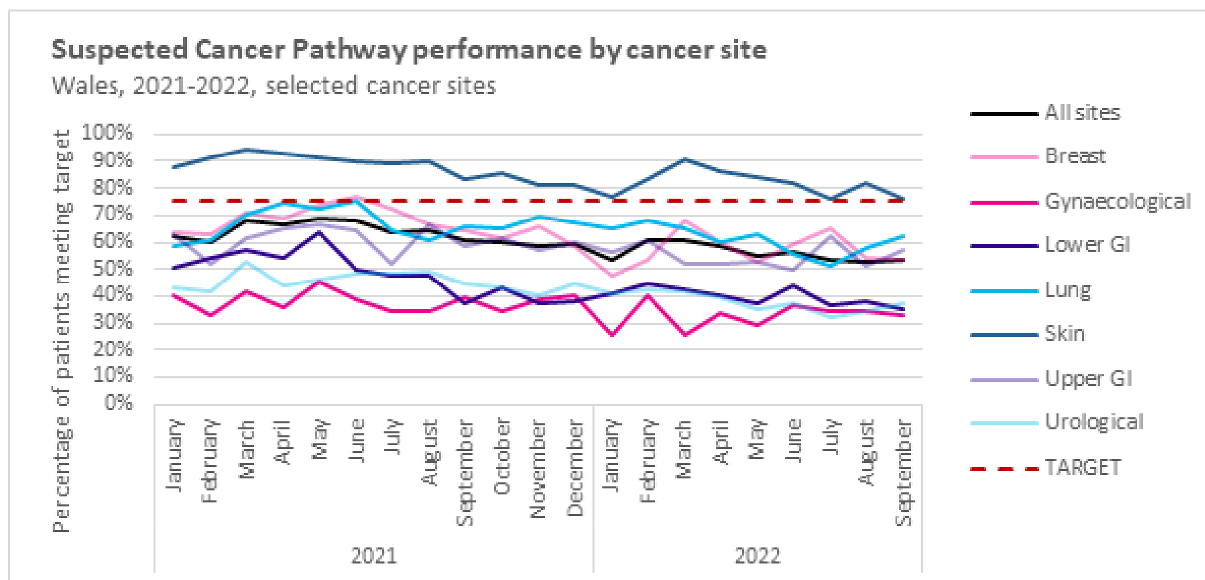
[21] Screening Division Inequalities Report 2020-21. Screening Division of Public Health Wales. June 2022. https://phw.nhs.wales/news/men-younger-people-and-those-living-in-the-more-deprived-communities-in-wales-show-lower-uptake-of-life-saving-screening-services1/screening-division-inequities-report-2020-21/

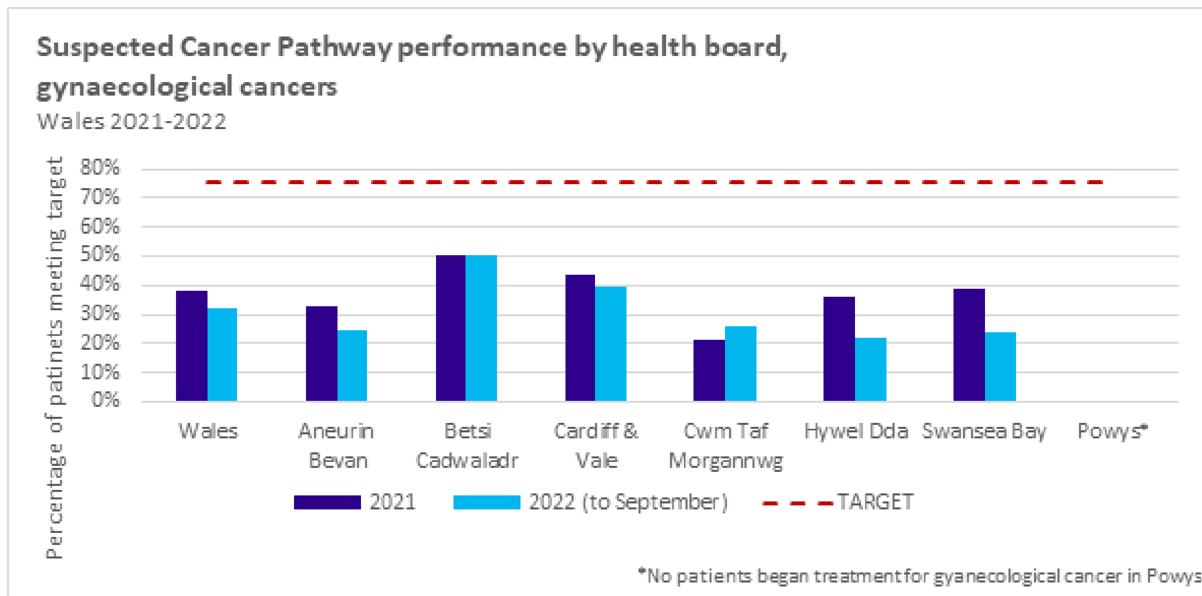
The prioritisation of pathways for gynaecological cancers as part of NHSE recovery, including how gynaecological cancer waiting lists compare to other cancers and other specialities

We do not have access to diagnostic waiting list data specifically for gynaecological cancers and therefore cannot make any comparison to the size of the waiting list to that for other cancers or other specialities. Cancer Research UK would like to see routine reporting of this data, broken down by cancer type, region and other relevant factors to ensure transparency and support identification of challenges in the system.

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).

As noted in the introduction to this inquiry, performance against the single cancer pathway for gynaecological cancers is poor, likely a result of long-standing pressures on the health system, exacerbated by the pandemic, and an increase in demand as people are encouraged to present. The graph below shows performance by pathway from January 2021 up to September 2022, highlighting that performance is among the worst for the gynaecological pathway and significantly below the single cancer pathway target of 75%. The second graph below highlights variation in the performance on this pathway between health boards, with most having declined performance in 2022 (to September) compared to 2021.





The Quality Statement for Cancer which describes what good quality cancer services should look like highlights the importance of fully embedded nationally optimised pathways including those for cervical, ovarian, endometrial and vulval cancers[22]. It is important that the implementation of these pathways is evaluated, and performance regularly monitored to ensure they are fully embedded to support planning and help reduce variation. Consideration should also be given to the role of audit and quality improvement efforts to support performance of the ovarian cancer pathway and reduce variation, including the forthcoming national clinical audit on ovarian cancer.

As a follow-up to the Quality Statement, the NHS Cancer Services Action Plan is due to be published in early 2023. This presents an opportunity to build on the principles laid out in the Quality Statement, to invest in the workforce and equipment required address long-waiting times and build sustainable services for the future.

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.

Currently in Wales data is publicly reported for all gynaecological cancers together and is not disaggregated to individual cancer types despite different gynaecological cancers having different pathways. This makes it challenging to understand poor performance in measures such as cancer waiting times where it is unclear whether one type of gynaecological cancer is driving poor performance or if there are wider system pressures for gynaecological pathways, including beyond cancer. In addition, demographic breakdowns are only available for age and sex.

Cancer Research UK would like to see disaggregated data routinely reported to provide invaluable information on service provision. This will provide transparency, help to understand how well services are performing generally and for different groups of patients, and support the identification, implementation and evaluation of service improvements, helping to ensure equitable access to timely, quality care.

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

[22] Welsh Government. The quality statement for cancer. Last updated May 2022. Accessed December 2022.

details of who is responsible for the leadership and innovation needed to improve cancer survival rates for women.

With the exception of cervical cancer screening, gynaecological cancers are not specifically mentioned in recent reports outlining quality standards for women's health in Wales, noted below. We do not know whether this will be reflected in the forthcoming plan for women's and girls' health.

This is in contrast to the Women's Health Strategy for England which highlights gynaecological cancers as the 7th most popular topic for inclusion and commits to several relevant actions including raising awareness, accelerating control of cervical cancer through HPV vaccination, making improvements to cervical screening (self-sampling, replacing call-recall system), introducing a best practice timed pathway for gynaecological cancers and a national clinical audit for ovarian cancer and funding research into barriers to early diagnosis of uterine cancer. It should be noted that several of these actions should also benefit women in Wales e.g. learning from evaluation self-sampling for cervical screening, research into barriers to early diagnosis, national clinical audit which will include Welsh patients. It will be important for Wales to ensure that any lessons learned from activity elsewhere are taken on board should these approaches also be implemented in Wales.

The Quality Statement for women and girls' health published by Welsh Government in July 2022 outlines expectations for health boards with regards to good quality health services for women and girls. Within this, cancer screening and diagnosis is listed as a condition where there is gender inequality and a need for gender competent services that women might require differently to men. However gynaecological cancers are not specifically mentioned.

Similarly, the 2022 Women's Health Wales quality statement published by the Women's Health Wales coalition, a coalition of patient advocates, condition-specific charities, UK-wide umbrella organisations and Royal Colleges, makes recommendations around the themes of equity, safety, effectiveness, efficiency, timeliness and person-centred care. This includes recommendations specific to cervical screening and cell changes noted above.

From the drafts we have seen through the Wales Cancer Alliance, gynaecological cancers will not be a specific focus on the forthcoming Wales NHS Cancer Services Action Plan – in line with the treatment of other cancer types within the plan. With regards to the leadership needed to drive innovation and improvement of outcomes, research from the International Cancer Benchmarking Partnership (ICBP) highlighted several aspects of leadership perceived as being important for improving outcomes by key informants across the ICBP jurisdictions[23].

This research found political will to be important in providing a strong mandate to those leading cancer care and the role of central bodies or agencies was described as 'pivotal' in relation to long-term follow through of plans and strategies, alongside clinical and health service leadership to drive implementation. The need for a 'coherent vision' from leaders at different levels of the system was also noted.

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.

[23] Morris M, Seguin M, Landon S, McKee M, Nolte E. Exploring the Role of Leadership in Facilitating Change to Improve Cancer Survival: An Analysis of Experiences in Seven High Income Countries in the International Cancer Benchmarking Partnership (ICBP). Int J Health Policy Manag. 2021 Aug 4. doi: 10.34172/ijhpm.2021.84.

In 2021/22 Cancer Research UK spent £388million on new and ongoing research including £9m on ovarian cancer focused research and £1m each on cervical and endometrial cancer focused research. Some of this research is being carried out in Wales, for example a study looking for biomarkers of ovarian cancer led by Dr Lavinia Margarit in Swansea[24] and other studies involving patients in Wales e.g. the ROCKeTS study which is looking at the use of existing tests to improve ovarian cancer diagnosis[25].

Research across the pathway will be crucial for improving gynaecological cancer outcomes, including research to support earlier detection and diagnosis. However, as has been the case right across the UK, capacity to deliver clinical cancer research in Wales has been a long-standing problem, hampering the ability to innovate and improve cancer outcomes. Issues that stem from years of underfunding and limited support[26]. For instance, during a survey of our research community last year, we found that scarcity of dedicated research time[27] [28] was the most common barrier to research in the NHS[29]. Even in Health Boards and Trusts considered research-active, 51% of NHS staff reported having insufficient access to research time.

For prospective researchers, the lack of dedicated time makes it harder to start getting involved in research; and for established researchers, the lack of time forces many to self-fund their research (e.g., by using annual leave)[30], which disincentivises them from staying in research and developing their expertise and experience. By limiting the develop of new researchers and underutilising the abilities of experienced researchers, this therefore restricts the NHS' capacity to conduct clinical research and its ability to expand that capacity.

Fortunately, clinical research's role in developing treatments and vaccines for COVID-19, including high-profile studies like RECOVERY, galvanised public and political enthusiasm for research. One of the outcomes of this has been a 10-year cross-UK Government strategy that aims "to create a world-leading clinical research environment" in the UK[31]. This strategy far from guarantees progress, though - as evidenced by the ongoing issues facing patient recruitment and study set-up.

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[24] https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-study-looking-for-biomarkers-of-ovarian-cancer#undefined

[25] https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-study-looking-at-current-tests-for-ovarian-cancer-to-help-improve-diagnosis-rockets#undefined

[26] Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf.

[27] Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf.

[28] Royal College of Physicians. 2020. Research for all? An analysis of clinical participation in research. Accessed 13 July 2021 via https://www.rcplondon.ac.uk/projects/outputs/research-all-analysis-clinical-participation-research., p. 8.

[29] Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf., p. 30

[30] Peckham, S. et al. 2021. Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research. Accessed 18 August 2021 via https://www.cancerresearchuk.org/sites/default/files/creating_time_for_research_february_2021_-_full_report-v2.pdf., p. 8.

[31] HM Government. 2021. Saving and Improving Lives: The Future of UK Clinical Research Delivery. Accessed 18 October 2021 via https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery

And simply recovering to a pre-pandemic 'normal' for cancer research will not be enough if Wales is to achieve world-class cancer outcomes. Instead, the Welsh Government must choose to go beyond recovery by expanding the capacity in Wales to deliver clinical cancer research, transforming how cancer research is delivered, including making it more efficient and equitable, and leveraging Wales' scientific strengths to deliver impactful innovations for cancer[32].

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

There is a huge amount of innovation taking place across the prevention, diagnosis and treatment of cancer, including seeking to improve outcomes for women with gynaecological cancers. For example, there is significant interest in the possibility of using liquid biopsies to support earlier cancer detection. This includes promising, early-stage research investigating the use urine tests to detect endometrial cancer[33], and research into multi-cancer early detection tests. However, the extent to which these tests will lead to a shift in gynaecological cancer outcomes is unknown, and if these tests do result in a meaningful difference to patients, there will be significant implications for health services.

We know that many innovations are not implemented effectively or equitably, if implemented at all. Effective planning to support swift adoption and implementation of innovations following evaluation is therefore key, particularly where an innovation is likely to be disruptive to existing pathways and services. In order to do this, it is important that the health system understands the innovations coming down the pipeline, when these will be ready for adoption, and how implementation across the health system can be supported to ensure equitable access. Wales should monitor developments in this area closely and should consider strategic opportunities to be a testbed for the rest of the UK.

To drive improvement in gynaecological cancer outcomes, we recommend that consideration is also given to optimal implementation of existing interventions, including sharing of best practice and where appropriate alternative approaches to service configuration. We know for example that research suggests that the significant variation observed between comparable countries in ovarian cancer outcomes is in part driven by provision of suboptimal treatment in the countries with worse outcomes[34,35]. This includes Wales where 3-year survival for patients aged 65-74 with later stage disease, the age and stage at which most patients are diagnosed, is 30% compared to 52% in Norway, the best performing country.

For more information and any queries on our submission, please contact Katie Till, Public Affairs Manager on

[32] Cancer Research UK. Beyond Recovery: The case for transforming UK clinical research. Accessed 10 Janurary 2023 via https://www.cancerresearchuk.org/sites/default/files/beyond_recovery_-_the_case_for_transforming_uk_clinical_cancer_research_february_2022.pdf

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Y Pwyllgor Iechyd a Gofal Cymdeithasol

—

Health and Social Care Committee

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Royal College of Emergency Medicine

24 April 2023

Dear Colleague

Inquiry into gynaecological cancers

The Health and Social Care Committee is looking at the experiences of women with symptoms of gynaecological cancer, how they are listened to and treated by healthcare professionals, and how services empower, care for and look after women diagnosed with a gynaecological cancer to ensure their physical, psychological and practical needs are met.

The Committee will be taking oral evidence during the summer term, following which we will produce a report of our findings and make recommendations for improvements to the Welsh Government. To help assist our deliberations, we would be grateful if you could provide us with the following information:

1. A recent International Cancer Benchmarking Partnership and Cancer Research UK (CRUK) study found that more patients are diagnosed with cancer in A&E in the UK than in other comparable high-income countries. It states that more than a third of patients in only find out they have the disease once they are in hospital. Could you explain why we have higher levels of emergency presentations in the UK?

2. The study found that those aged 75 and over were more likely to be diagnosed in an emergency. What is your understanding of why this is?

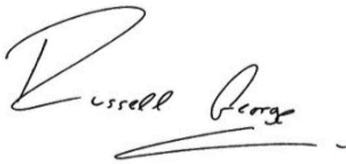
3. The study also found that cancers that often have non-specific, vague symptoms, such as ovarian cancer, are more likely to be diagnosed through emergency routes. Are you aware of any analysis that has been undertaken to better understand the presentation of different types of gynaecological cancers in A&E?

4. What action do you believe is needed to ensure fewer patients are being diagnosed with cancer after an emergency referral or visit to A&E. What action do you believe is needed to improve the assessment of patients with late stage cancer symptoms admitted through A&E and to ensure new cancer patients (admitted through A&E, who usually have advanced disease) have prompt access to cancer services and support.

5. Any views on the way acute oncology teams currently operate in Wales in terms of providing an emergency cancer service to hospitals with A&E departments.

To ensure we can take your answers into account as we take oral evidence, we would be grateful for a response by 12 May 2023.

Yours sincerely



Russell George MS
Chair, Health and Social Care Committee

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

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Mr Russell George MS
Welsh Parliament
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17th May 2023

Dear Russell George MS,

Thank you for your request to give evidence at the Health and Social Care Committee on gynaecological cancer, and apologies for a delayed response.

After some discussion, we think that these questions fall outside RCEM's remit. Although gynaecological cancers may on occasion present to the Emergency Department, the management of these conditions is not usually handled by emergency medicine doctors, so we do not feel we are best placed to answer these questions.

These issues would better be addressed by colleagues in Gynaecology (how services are planned and provided), Public Health (why patients choose one route into healthcare over another) or Primary Care (why patients end up in the emergency department rather than being referred on Urgent Suspected Cancer pathway).

Once again thank you for asking for our assistance on such an important issue. We look forward to receiving future requests for evidence.

If you would like to discuss this further or any other matters, please do let us know. It would be great to meet to discuss pressures on emergency care more generally in Wales and possible solutions.

Yours sincerely,

Dr Suresh Pillai
Vice President of the Royal College of Emergency Medicine (Wales)

Excellence in Emergency Care

Incorporated by Royal Charter, 2008
Registered Charity Number: 1122689
VAT Reg. No. 173205823
Scottish Charity Number: SC044373

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Y Pwyllgor Iechyd a Gofal Cymdeithasol

—

Health and Social Care Committee

Y Pwyllgor Cydraddoldeb a Chyfiawnder Cymdeithasol

—

Equality and Social Justice Committee

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Jane Hutt MS
Minister for Social Justice

3 January 2023

Dear Jane

Equality, Local Government and Communities Committee report: Into sharp relief: inequality and the pandemic

The Equality and Social Justice Committee and Health and Social Care Committee have recently been contacted by RNIB Cymru about a report of the previous Senedd's Equality, Local Government and Communities (ELGC) Committee regarding inequality and the pandemic.

RNIB Cymru has highlighted recommendation 37 of that report, which called for the Welsh Government to appoint an accessibility lead within the Welsh Government to oversee the production of all key public health and other information in accessible formats. This recommendation was accepted by the Welsh Government in its response to the report (September 2020), but RNIB Cymru is concerned that this has not yet been implemented.

This issue was raised again in a report by the Health and Social Care Committee in April 2022.[1] The Welsh Government accepted the Health and Social Care Committee's recommendation. However, the narrative in the response focused on the establishment of the Disability Rights Taskforce, a review of the use of British Sign Language and the preparation of guidance for staff prepared by the Access to services (including accessible communications) working group rather than directly addressing the

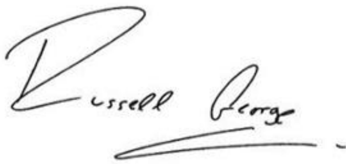
[1] Health and Social Care Committee, Waiting well? The impact of the waiting times backlog on people in Wales, April 2022, recommendation 13

appointment of an accessibility lead within the Welsh Government to oversee the production of all key public health and other information in accessible formats.

We would be grateful if you could provide an update in relation to the ELGC Committee's initial recommendation, including timescales for its implementation and any reasons why the appointment of an accessibility lead was omitted from the subsequent response to the Health and Social Care Committee.

We are copying this letter to the Minister for Health and Social Services.

Yours sincerely



Russell George MS
Chair, Health and Social Care Committee

Jenny Rathbone MS
Chair, Equality and Social Justice Committee

cc Eluned Morgan MS, Minister for Health and Social Services

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

Jane Hutt AS/MS
Gweinidog Cyfiawnder Cymdeithasol a'r Prif Chwip
Minister for Social Justice and Chief Whip

Llywodraeth Cymru
Welsh Government

Russell George MS
Chair, Health and Social Chair Committee

Jenny Rathbone MS
Chair, Equality and Social Justice Committee

2 June 2023

Dear Russell and Jenny,

Equality, Local Government and Communities Committee report: Into sharp relief: Inequality and the pandemic

Please accept my apologies for the delay in responding to your letter in relation to RNIB highlighting recommendation 37 of a report to the previous Senedd's Equality, Local Government and Communities Committee regarding inequality and the pandemic. This recommendation calls for an accessibility lead within the Welsh Government to oversee the production of all key public health and other information in accessible formats. I have copied this letter to the Minister for Health and Social Services as this recommendation clearly impacts on both of our portfolio areas.

The Welsh Government is fully committed to ensuring accessibility of all information for all Welsh citizens. You will be aware during the Covid-19 pandemic we ensured all public information was fully accessible including the presence of a British Sign Language (BSL) interpreter at each of our Covid-19 news conferences and ensuring that large print and braille were available on request alongside other accessible formats on key products, such as the shielding letters from the Chief Medical Officer.

During the pandemic we established an Accessible Communication Group, to discuss and overcome the barriers stopping people from accessing information. This Group includes a wide range of organisations, who have testified to the difficulties that some of those with impairments experienced when trying to access clear and concise information during the coronavirus pandemic. The Group also includes organisations who represent refugees, children and the Gypsy, Roma Traveller communities. The group co-created a guidance document which sets out the standards that the Welsh Government will meet to make sure that communications are accessible and meet the needs of people across Wales.

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

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

We continue to maintain and improve our advice and guidance on accessibility on a cross-government basis. This sets clear and commonly understood standards which apply to the whole government and provides a framework for all departments to provide key information in a way which is accessible to all. It is the responsibility of all parts of the government to ensure that the material they produce aligns with these standards. As part of the development of those standards, it is clear that given the breadth and complexity of its policy responsibilities, the Welsh Government generates and publishes a very significant amount of material every year, over which it would likely be impossible for one individual to maintain effective oversight. We will continue to keep the recommendation for a single lead under consideration, but the current approach of system-wide responsibility for accessibility, carried out on a cross-government basis, and with a foundation of common standards, enables effective delivery to meet the needs of the people of Wales.

The Social Services and Well-being (Wales) Act 2014, and supporting codes of practice set out requirements, in line with the Equality Act 2010, to ensure equality of access to services. This includes local authorities providing information advice and assistance relating to care and support, which is accessible and meets the needs of the population. Also, in delivering care and support, local authorities must use the language of need and preferred means of communication, for example British Sign Language, braille, large print versions.

This means people must be able to fully participate in the assessment of their potential needs. Everyone must be able to express their views, wishes and feelings as an equal partner about what matters to them and what they want to achieve. Our 2014 Act requires that local authorities must support people to be able to do this.

The 2014 Act also requires Regional Partnership Boards to assess and plan for the care and support needs of their populations. Guidance sets out core themes for these population assessments and area plans, including for those with sensory impairments.

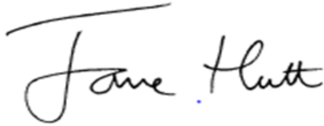
The Welsh Government is fully committed in supporting all disabled people in Wales. We have set up the Disability Rights Taskforce which will run until 2024. It brings together people with lived experience, Welsh Government Policy Leads and representative organisations to identify the issues and barriers that affect the lives of many disabled people. The Taskforce works within the scope of the Welsh Government's legal remit and not in areas that solely fall under the UK Government's responsibilities.

The Taskforce established a number of workstreams which were identified as priority areas:

- Embedding and Understanding of the Social Model of Disability (across Wales)
- Access to Services (including Communications and Technology)
- Independent Living: Health, Wellbeing and Social Care
- Travel
- Employment and Income
- Affordable and Accessible Housing
- Children and Young People
- Criminal justice System

The Working Groups have a range of stakeholders which includes organisations that support disabled people, disabled people with lived experience and Welsh Government policy leads. These include blind and partially sighted members who provide lived experience to working groups, including travel and access to services. The working groups' co-produced recommendations will form an action plan, to improve the lives of disabled people in Wales.

Yours sincerely,



Jane Hutt AS/MS
Gweinidog Cyfiawnder Cymdeithasol a'r Prif Chwip
Minister for Social Justice and Chief Whip

Y Pwyllgor Deddfwriaeth, Cyfiawnder a'r Cyfansoddiad
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Legislation, Justice and Constitution Committee

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Llyr Gruffydd MS
Chair, Climate Change, Environment, and Infrastructure Committee

Paul Davies MS
Chair, Economy, Trade, and Rural Affairs Committee

Russell George MS
Chair, Health and Social Care Committee

Mark Isherwood MS
Chair, Public Accounts and Public Administration Committee

12 May 2023

Dear Chairs

You will be aware that my Committee has been maintaining an oversight of the UK Common Frameworks programme while your committees, and other parliamentary committees in the UK, have been undertaking scrutiny of individual frameworks.

We recently agreed to make recommendations to the Welsh Government in respect of cross-cutting issues arising from this scrutiny. Today we have laid our report which includes these recommendations.

We have also sought a debate in Plenary to note the report on Wednesday 12 July 2023. We hope this will also provide an opportunity for you, and members of your committees, to highlight issues arising from your scrutiny of individual common frameworks.

Yours sincerely,

Huw Irranca-Davies

Huw Irranca-Davies
Chair

Senedd Cymru
Welsh Parliament

Y Pwyllgor Deddfwriaeth, Cyfiawnder a'r Cyfansoddiad
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Legislation, Justice and Constitution Committee

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Eluned Morgan MS
Minister for Health and Social Services

15 May 2023

Dear Eluned

Healthcare (International Arrangements) (EU Exit) Regulations 2023

At our meeting on 2 May 2023 we considered your letter of 25 April in which you advised my Committee that the UK Government intends to make and lay the Healthcare (International Arrangements) (EU Exit) Regulations 2023 (the HIA Regulations) in early June.

We noted that the HIA Regulations will extend to the whole of the UK and that they 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 (the HEEASA Regulations), which are made in relation to the provision of reciprocal healthcare in European Economic Area (EEA) states and Switzerland.

We have a number of questions to ask you on the HIA Regulations. I would be grateful to receive a response to the questions set out in the Annex by 31 May.

I am copying this letter to the Health and Social Care Committee.

Yours sincerely,

Huw Irranca-Davies

Huw Irranca-Davies
Chair

Senedd Cymru
Welsh Parliament

ANNEX

Question 1:

In the letter you state that the HIA Regulations "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". When will section 162 of the Health and Care Act 2022 (the 2022 Act) be brought into force?

Question 2:

In your letter you state "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." You also state "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." We would be grateful to receive further clarity on the specific differences between the HIA Regulations and the HEEASA Regulations and what is meant by the phrase "broadly retains the status quo".

Question 3:

You will be aware that, in our report on The Welsh Government's Legislative Consent Memorandum on the Health and Care Bill (December 2021 report) and in our subsequent report on The Welsh Government's Supplementary Legislative Consent Memoranda (Memorandum No. 2 and Memorandum No. 3) on the Health and Care Bill (February 2022 report), we expressed concerns about what became section 162 of the 2022 Act, the breadth of delegated powers it provided to Ministers, and the consequences such regulations could have for NHS bodies in Wales.

Conclusion 6 in our February 2022 report said "The Welsh Ministers should make any necessary regulations in devolved areas for the purpose of giving effect to international healthcare agreements. Where they do not do so, and the power to confer relevant functions onto the Local Health Boards regarding healthcare agreements is instead exercised by the Secretary of State, the Welsh Ministers must provide full detail and an explanation to the Senedd in advance of such regulations being made by the Secretary of State."

We acknowledge that your letter of 25 April does notify the Senedd of the planned making of the HIA Regulations by the Secretary of State. We would welcome confirmation and clarity as to how Welsh Local Health Boards have been consulted on the HIA Regulations.

Question 4:

In your letter you state "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."

As highlighted in the previous question, conclusion 6 in our February 2022 report recommended that the Welsh Government should make any necessary regulations in devolved areas for the purpose of giving effect to international healthcare agreements.

a) Can you explain why you consider it "more pragmatic and efficient to have UK Government carry out this work on [your] behalf".

b) Can you confirm that, when the power to confer relevant functions onto the Local Health Boards regarding healthcare agreements is exercised by the Secretary of State in the future, the Welsh Ministers will provide full details and an explanation to the Senedd in advance of such regulations being made.

c) What assessments will be undertaken by the Welsh Government of the implications for Welsh Local Health Boards before any consent is given to the UK Government to make further regulations which add countries to the Schedule?

d) Can you confirm if you are aware of any upcoming international healthcare agreements.

e) How are the Welsh Government and Welsh Local Health Boards being included in negotiations, or being sufficiently consulted, about ongoing and future agreements with other countries?

f) Can you confirm whether these Regulations are being taken through the processes outlined in the intergovernmental Memorandum of Understanding in Respect of the Consultation Process for International Healthcare Agreements and their Implementation (a version of which was made available to us in February 2022).

Question 5:

In your letter you state "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."

We would welcome further explanation and clarity on your statement that "having the UK Government make this provision for Wales would not be detrimental to the policy position in this area".

Huw Irranca-Davies MS
Chair,
Legislation, Justice and Constitution Committee

SeneddLJC@senedd.wales

2 June 2023

Dear Huw

Thank you for your letter of 15 May concerning the Healthcare (International Arrangements) (EU Exit) Regulations 2023 ("the HIA Regulations"). I have addressed your questions regarding the HIA Regulations below.

Question 1

In the letter you state that the HIA Regulations "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". When will section 162 of the Health and Care Act 2022 (the 2022 Act) be brought into force?

My officials expect the commencement to be this summer based on the information provided by their UK Government counterparts.

Question 2

In your letter you state "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." You also state "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." We would be grateful to receive further clarity on the specific differences between the HIA Regulations and the HEEASA Regulations and what is meant by the phrase "broadly retains the status quo".

The Healthcare (European Economic Area and Switzerland Arrangements) (EU Exit) Regulations 2019 (“HEEASA regulations”):

- confer a duty on the UK NHS Business Services Authority (NHS BSA) to, subject to instructions given by the Secretary of State, make payments on a UK wide basis under section 1 of the Healthcare (European Economic Area and Switzerland Arrangements) Act 2019 (“the 2019 Act”) (which enables the Secretary of State to make payments, or arrange for payments to be made, in respect of the cost of healthcare provided in an EEA State or Switzerland), and to assist the Secretary of State with the exercise of the Secretary of State’s functions in relation to making such payments, giving effect to healthcare agreements and arrangements and the provision of healthcare in member states;
- confer functions to give effect to obligations and commitments of the UK under healthcare agreements or arrangements, on NHS BSA and the Secretary of State;
- impose information and advice functions on NHS BSA (i.e. to establish and maintain a public information and advice service);
- confer S2 planned treatment functions on NHS England, Welsh Local Health Boards (LHBs) and Scottish health boards (i.e. to carry out clinical determination of applications in accordance with international healthcare agreements and arrangements);
- provide for the Secretary of State and Ministers of the Devolved Governments to be able to determine, along with relevant health boards, the NHS S2 (planned) treatment applications.

The HIA Regulations ‘broadly retain the status quo’ as the roles of the Secretary of State, NHS BSA, and relevant health boards (e.g. Welsh LHBs in relation to Wales) within the legal framework broadly remain the same.

Section 162 of the Health and Care Act 2022 (“the 2022 Act”) removed the Secretary of State’s wider power to make healthcare payments in section 1 of the 2019 Act and the power to make regulations in relation to healthcare and healthcare agreements in section 2 of the 2019 Act. Those powers were created to support people to access healthcare in the EEA and Switzerland in the event of leaving the EU without an agreement and such measures were no longer needed. Section 162 replaced the previous powers with a healthcare agreements and payments discretionary regulation-making power. As a result, the HIA Regulations enable the Secretary of State to, on a UK wide basis, make a payment and arrange for the making of the payment, in respect of healthcare provided in a listed country under a healthcare agreement and to make payments (otherwise than under a healthcare agreement) in respect of healthcare provided in a listed country where the Secretary of State considers exceptional circumstances justify the payment (with the ability for referrals for applications or claims for such payments to be made by NHS BSA, NHS England, Welsh LHBs and Scottish local health boards).

Under the HIA Regulations, the NHS BSA is still required to give effect to the obligations and commitments of the UK under relevant healthcare agreements, to assist the Secretary of State with their exercise of functions in relation to relevant healthcare agreements and the provision of healthcare in listed countries and to establish and maintain a public information and advice service. Relevant health boards (e.g. Welsh LHBs in relation to Wales) are also still required to carry out clinical determinations of S2 planned treatment applications, in accordance with relevant healthcare agreements.

In addition, along with a number of technical changes the HIA Regulations also:

- list countries party to international healthcare agreements with the UK (whereas the HEEASA Regulations required the Secretary of State to publish and maintain a separate list of international healthcare agreements);
- require the Secretary of State, NHS BSA, NHS England, Welsh LHBs and Scottish health boards to establish and publish procedures for the determination of applications and claims within their remit, which must include provision for a review process.

The HIA Regulations do not carry forward the power from HEEASA enabling the Secretary of State and Ministers of the Devolved Governments to determine, along with relevant health boards, NHS S2 (planned) treatment applications. However, this power in the HEEASA Regulations has never been used in Wales and there are no foreseeable circumstances where the Welsh Ministers would wish to determine an S2 (planned) treatment application, as such applications are subject to clinical assessment which sits with the LHBs. The Welsh Government does not have the required clinical expertise to make such a determination and therefore provide the relevant advice to Ministers in this regard.

As section 162 of the 2022 Act also enabled regulations to be made in this area which implement comprehensive reciprocal agreements with countries outside the EEA and Switzerland, the HIA Regulations apply to listed relevant healthcare agreements with Rest of the World countries.

Question 3

You will be aware that, in our report on The Welsh Government's Legislative Consent Memorandum on the Health and Care Bill (December 2021 report) and in our subsequent report on The Welsh Government's Supplementary Legislative Consent Memoranda (Memorandum No. 2 and Memorandum No. 3) on the Health and Care Bill (February 2022 report), we expressed concerns about what became section 162 of the 2022 Act, the breadth of delegated powers it provided to Ministers, and the consequences such regulations could have for NHS bodies in Wales.

Conclusion 6 in our February 2022 report said "The Welsh Ministers should make any necessary regulations in devolved areas for the purpose of giving effect to international healthcare agreements. Where they do not do so, and the power to confer relevant functions onto the Local Health Boards regarding healthcare agreements is instead exercised by the Secretary of State, the Welsh Ministers must provide full detail and an explanation to the Senedd in advance of such regulations being made by the Secretary of State."

We acknowledge that your letter of 25 April does notify the Senedd of the planned making of the HIA Regulations by the Secretary of State. We would welcome confirmation and clarity as to how Welsh Local Health Boards have been consulted on the HIA Regulations

The LHBs have been kept updated by my officials on the progress of the HIA Regulations and specifically consulted on the area of the HIA Regulations that imposes a new duty on them (ie, the requirement for LHBs to establish and publish procedures for the determination of S2 applications, which include provision for a review process). The LHBs have also been consulted by UK Government on the process and guidance for applying to the Secretary of State for healthcare payments in exceptional circumstances as these may be sought on behalf of a patient by their LHB.

Question 4

In your letter you state "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." As highlighted in the previous question, conclusion 6 in our February 2022 report recommended that the Welsh Government should make any necessary regulations in devolved areas for the purpose of giving effect to international healthcare agreements.

a) Can you explain why you consider it "more pragmatic and efficient to have UK Government carry out this work on [your] behalf".

Each time the UK Government enters into a new healthcare agreement with a country or territory, the HIA Regulations will need to be amended to add that country or territory to the Schedule on a UK wide basis, to give effect to and implement the agreement across the UK. Given that UK Government intends to seek agreements with a number of countries in the coming years, there could be a necessity for an ongoing series of amendments to be made to the Schedule. The UK Government will be required to amend the Schedule each time they enter into a new healthcare agreement, at least in relation to England. As they also have the competence to amend the Schedule on a UK wide basis, it is pragmatic and efficient for them to apply any such amendment to Wales, given that an equivalent amendment would be required in relation to Wales in any event.

In addition, as set out below, the impact on the LHBs of listing such agreements in the HIA Regulations is likely to be extremely low and I thus consider legislating separately for Wales when a new agreement is required to be listed would be neither the most appropriate way to give effect to the necessary changes, nor a prudent use of Welsh Government resources given other important priorities.

b) Can you confirm that, when the power to confer relevant functions onto the Local Health Boards regarding healthcare agreements is exercised by the Secretary of State in the future, the Welsh Ministers will provide full details and an explanation to the Senedd in advance of such regulations being made.

I can confirm that the WG will continue to inform the Senedd where the UK Government exercises a delegated legislative power in a devolved area in relation to Wales explaining the rationale for this.

c) What assessments will be undertaken by the Welsh Government of the implications for Welsh Local Health Boards before any consent is given to the UK Government to make further regulations which add countries to the Schedule?

There is no statutory requirement for UK Government to seek the Welsh Minister's consent in respect of further regulations adding further countries to the Schedule. Following the commencement of section 162 of the Health and Care Act 2022 and the coming into force of the HIA Regulations, section 5 of the Healthcare (International Arrangements) Act 2019 (formerly titled the Healthcare (European Economic Area and Switzerland Arrangements) Act 2019), will contain is a statutory requirement for the Secretary of State to consult with Welsh Ministers before making regulations that contain provision which is within the legislative competence of the Senedd. This should be carried out under the terms of the Intergovernmental Memorandum of Understanding in Respect of the Consultation Process for International Healthcare Agreements and their Implementation Regulations ("the MOU") (annexed to this letter).

Question 5

In your letter you state "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." We would welcome further explanation and clarity on your statement that "having the UK Government make this provision for Wales would not be detrimental to the policy position in this area".

Our policy position in this regard is the currently same as the UK Government's and I do not anticipate this changing. The provisions of the HIA regulations thus align with our policy. As set out above, should our policies in this area diverge in the future we have the power under section 2A of the Healthcare (International Arrangements) Act 2019 to make our own regulations to implement certain changes in Wales, provided those changes are within devolved competence, the scope of which is prescribed by section 2A(2) and (4)(b) of the Act. Thus, having the UK Government make this provision for Wales is not detrimental to current or future Welsh policy in this area.

I trust this answers your questions.

This letter has been copied to Russell George MS, the Chair of the Health and Social Care Committee.

Yours sincerely

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

MEMORANDUM OF UNDERSTANDING BETWEEN THE UK GOVERNMENT SECRETARY OF STATE FOR THE DEPARTMENT OF HEALTH AND SOCIAL CARE AND THE SCOTTISH MINISTERS, THE WELSH MINISTER FOR HEALTH AND SOCIAL SERVICES, AND THE MINISTER OF HEALTH FOR NORTHERN IRELAND (THE "DEVOLVED GOVERNMENTS")

In Respect of the Consultation Process for International Healthcare Agreements and their Implementation

CONTENTS

A. INTRODUCTION
1. Overview and Scope
2. Overarching Principles

B. CONSULTATION PROCESS – POLICY AND AGREEMENTS
3. Policy Mandate and Formation
4. Negotiations and Drafting of International Agreements
5. Ministerial Engagement
6. Dispute Resolution
7. Confidentiality

C. CONSULTATION PROCESS - IMPLEMENTATION AND REVIEW
8. Regulations under Healthcare (International Arrangements) Act 2019
9. Operational Implementation
10. Review

D. DATA SHARING
E. SIGNATORIES
ANNEX A

A. INTRODUCTION

1. Overview and Scope

1.1 This Memorandum sets out the understanding of the United Kingdom (UK) Government Secretary of State for the Department of Health and Social Care (DHSC) and the Scottish Ministers, the Welsh Minister for Health and Social Services, and the Minister of Health for Northern Ireland ("the Devolved Governments"), on the Healthcare (International Arrangements) Act 2019 (HIAA). It sets out the arrangements for consultation and meaningful engagement in the formulation, negotiation, and implementation of new, revised and updated international reciprocal healthcare agreements, which go further than the consultation duty under section 5 of HIAA (see para 1.3 below).

1.2 The implementation of international reciprocal healthcare agreements, which include reimbursement and the exchange of data, is enabled by HIAA. Sections 2 and 2A of HIAA confer powers on the Secretary of State and Ministers in the Devolved Governments to make regulations for the purpose of giving effect to international reciprocal healthcare agreements. The power to make regulations is conferred on Ministers within the Devolved Governments where it would be within their devolved competence to make such provision.

1.3 This Memorandum also sets out how the Secretary of State will meet the legal requirement to consult with the Devolved Governments before making regulations under section 2 that contain provisions within the legislative competence of the devolved legislatures. However, the UK Government will

proceed in accordance with the convention that the UK Parliament would not normally legislate with regard to devolved matters except with the agreement of the devolved legislature.

1.4 This Memorandum does not create any additional legally enforceable rights and obligations between the parties. Nothing in this Memorandum should be construed as conflicting with the Belfast Agreement.

Responsibilities for Negotiating and Delivery of International Reciprocal Healthcare Agreements

1.5 The UK Government is responsible for international relations and has overall responsibility for concluding treaties and other international agreements on behalf of the United Kingdom.

1.6 The implementation of international healthcare obligations will usually be within the devolved competence of the Devolved Governments when the obligations relate to devolved healthcare provision within those countries.

2. Overarching Principles

2.1 DHSC and the Devolved Governments are committed to delivering collectively a reciprocal healthcare policy that works for residents throughout the UK as a whole in order to realise the broad benefits of international reciprocal healthcare agreements.

2.2 The arrangements set out in this Memorandum of Understanding will be underpinned by the principles of open communication, consultation, and cooperation. DHSC and the Devolved Governments are committed to making representations to each other as necessary in sufficient time for those views or concerns to be fully considered.

2.3 DHSC and the Devolved Governments recognise the importance of ensuring international reciprocal healthcare policy alignment for all healthcare systems across the UK and will work closely to develop and maintain a cohesive international reciprocal healthcare system that delivers for all UK residents. At the beginning of each stage of the process, DHSC and the Devolved Governments will agree a feasible timetable for all parties.

2.4 For those negotiations where DHSC is not the lead Government Department, DHSC and the Devolved Governments will proceed on the principles set out in this Memorandum of Understanding on specific international reciprocal healthcare elements.

B. CONSULTATION PROCESS – POLICY AND AGREEMENTS

3. Policy Mandate and Formation

Strategy Formulation

3.1 This Memorandum establishes arrangements (Annex A – Stage 1) for collaborative policy development and analysis where responsibility for implementation of those policies is within devolved competence. These arrangements provide a vehicle for meaningful engagement on policy proposals to take into negotiations. The arrangements will apply to the formation of overarching policy and model agreements as well as to individual policy mandates for reciprocal healthcare agreements with third countries. These arrangements will apply to any proposals for the review or amendment of implemented healthcare agreements with a view to reaching consensus by all parties on the proposed action. The Governments recognise that cooperation is necessary to meet their respective policy objectives.

3.2 DHSC will consult the Devolved Governments in writing where policy areas engage or have the potential to engage devolved competence. In addition, to support the effective implementation of

international healthcare agreements, DHSC will engage with the Devolved Governments on the full scope of any future international healthcare agreements to ensure that healthcare provisions work optimally across the whole of the UK. Consultation will be as early as possible and at a formative stage of policy development, as officials start to consider policy proposals, political steers, or third country requests for reciprocal healthcare agreements. The Devolved Governments will respond in writing, by an agreed date whenever possible, to DHSC setting out their views and any concerns about what is proposed on behalf of their Ministers and Executive. The Devolved Governments will be sent copies of papers and be invited to fully participate in meetings on subjects in which they have a devolved policy interest. Given the complexity of agreements, the strategy formulation will include engagement with all key partners as outlined in Annex A - Stage 1.

3.3 The arrangements will include regular informal and working level engagement between officials and Ministers to discuss policy proposals on the strategic direction for new international reciprocal healthcare agreements, or for proposals to renegotiate existing international reciprocal healthcare agreements and any projected impact assessments of those proposals. DHSC will arrange a regular international reciprocal healthcare meeting with the Devolved Governments on the issues, to be held with a frequency agreed with the Devolved Governments. DHSC will ensure that the Devolved Governments are given as much time as possible to properly consider proposals and feedback their views.

3.4 In order to enable each Government to operate effectively, the Governments will aim to provide each other with full and open access to policy information, for example data on S2 planned treatment, that may be requested where reasonable and appropriate. The Devolved Governments will be invited to contribute to impact assessments, on areas of devolved competence, which will be shared to support transparency on cost and benefits and inform evaluations of impact across the UK. The emphasis will always be on exchanging information where this proves possible to ensure a consistent approach to reciprocal healthcare policy and consideration of impact.

3.5 There will always be discussions between DHSC and Devolved Government officials in the first instance to reach a view on the policy before DHSC and Devolved Government officials put advice to their respective Ministers. DHSC officials will clearly identify where the views of the Devolved Government Ministers are still pending in their advice to DHSC Ministers. DHSC officials will ensure that the views of the Devolved Government Ministers are represented to DHSC Ministers in a timely manner, as soon as these are known. DHSC Ministers will write to Devolved Government Ministers to set out the policy proposals they endorse, giving them a reasonable period to respond, in order to build consensus on the direction to be taken in negotiations. Ministers from the Devolved Governments will provide their responses to DHSC Ministers by an agreed date whenever possible.

Agreement of Negotiating Mandate

3.6 All Devolved Governments will have the opportunity to influence the overall objective and shape of the mandate, noting this may be subject to change. As at Stage 1 (Annex A), the Devolved Governments will be sent copies of papers as early as possible and be invited to fully participate in meetings to build consensus on the negotiating mandate with regular informal and working level engagement between officials and Ministers to discuss policy proposals. Discussions between officials will be arranged with a frequency agreed with the Devolved Governments and depending on the timeframes for negotiations.

3.7 DHSC will share draft mandate text with the Devolved Governments for consultation and comment, prior to policy mandates going through cross UK Government write round and before publication. This will ensure appropriate consideration to the views of the Devolved Governments and that the negotiation mandates are acceptable to all parts of the UK (Annex A - Stage 2).

3.8 The Governments agree to share their respective legislative requirements at an early stage in the policy development process to provide for a common understanding of what will be necessary for implementation of a UK-wide agreement, to ensure transparency and timely consideration to feed into negotiations. This will be discussed by policy officials with policy and legal teams providing assurance on necessary implementation steps.

4. Negotiations and Drafting of International Agreements

4.1 DHSC will consult the Devolved Governments about the formulation of the UK Government's position for international reciprocal healthcare negotiations and any resulting deviations to the mandate where this has, or may have, an impact on devolved responsibilities. In such cases the Devolved Governments will be given early sight of evolving negotiating positions, with a reasonable period for consultation and comment, in order to reflect the views of the Devolved Governments in determining the approach for handling discussions. The Devolved Governments will respond with any concerns by an agreed date whenever possible.

4.2 Where there are deviations to the mandate DHSC officials will write to the Devolved Governments setting out the deviations for their review and consideration where this has, or may, impact on devolved responsibilities. Concession requests will be considered at official level in the first instance, with advice being put to DHSC Ministers and Devolved Government Ministers at the same time. DHSC will clearly identify where the views of the Devolved Government Ministers are still pending and will ensure that the views of the Devolved Government Ministers are represented to DHSC Ministers in a timely manner, as soon as these are known. Ministers from the Devolved Governments will provide any comments by an agreed date whenever possible. DHSC Ministers will consider any representations made and keep Devolved Government Ministers informed of any decisions by an agreed date whenever possible.

4.3 DHSC will provide regular updates to the Devolved Governments on the progress of negotiations including tracking documents and timelines (Annex A - Stage 3).

4.4 Once agreement with the third country has been reached in principle, advice will be provided to Ministers and the Devolved Governments on the final agreement. The legal text is the final output of the negotiations and will be drafted to reflect the policy proposals as they are developed (Annex A - Stage 4). DHSC will always seek to find consensus that the agreement reflects the policy position and assessment of implications and their suitability for implementation across the UK.

5. Ministerial Engagement

5.1 Engagement between Ministers may take place at any point throughout the consultation process set out in this Memorandum of Understanding upon request of any of the Ministers at DHSC or the Devolved Governments. DHSC and the Devolved Governments are committed to constructive and proportionate engagement with Ministers through the optimal engagement forum and commit to arranging ministerial discussions if required and desirable, coupled with formal written communications at key points on all negotiations.

6. Dispute Resolution

6.1 While the aim of this Memorandum of Understanding is to facilitate the consultation process on reciprocal healthcare agreements and section 2A of the HIAA provides powers for the Devolved Governments to introduce regulations when deemed necessary, recognising devolved competency, in circumstances where agreement cannot be reached, all efforts should be made to resolve disputes by an agreed date through the following process where possible:

- i. In the first instance, concerns will be raised informally and at working level between policy officials. All officials should fully commit themselves to achieving agreement if possible.
- ii. Where officials cannot reach an agreement, the issue should be brought to the attention of more senior officials. Senior officials should make every effort to resolve the problem without the need for ministerial engagement.
- iii. If no agreement is reached at official level, concerns should be raised at ministerial level. The final escalation point will be to Ministers.

6.2 The UK Government will proceed in accordance with the convention that the UK Parliament would not normally legislate with regard to devolved matters except with the agreement of the devolved legislature. In the event that no resolution can be found, there will be an exchange of letters between

Ministers. This would provide the opportunity for a Devolved Government to set out its position, and for the Secretary of State to explain the reasons for the final position and how the UK Government has sought to reach agreement with the Devolved Governments. If the Secretary of State decides to proceed without resolution and guided by the principles set out in this Memorandum, the exchange of letters should be made available to both Houses of Parliament.

6.3 The process outlined above gives the Governments an opportunity to resolve disputes, but there is not a formal obligation to follow this process.

7. Confidentiality

7.1 Each Government will wish to ensure that the information it supplies to others is subject to appropriate safeguards in order to avoid prejudicing its interests. Complete confidentiality is often essential in matters touching on international relations and in formulating a UK policy position. The effectiveness of arrangements agreed under this Memorandum of Understanding will rely on mutual respect for the confidentiality of information exchange. The Governments accept that in certain circumstances a duty of confidence may arise and will between themselves respect legal requirements of confidentiality. Each Government can only expect to receive information if it treats such information with appropriate discretion and not share anything publicly without agreement of all parties.

7.2 There will also be a common approach to the classification and handling of sensitive material. Information will be shared at the appropriate classification level decided by the administration providing the information. Each Government will treat information which it receives in accordance with the restrictions specified. In the event that a Government is subject to a legal obligation to disclose information, for example a freedom of information request, the Governments will consult each other and assist the Governments in complying with their legal obligations.

C. CONSULTATION PROCESS - IMPLEMENTATION AND REVIEW

8. Regulations under HIAA

8.1 In line with the principles set out above, it is necessary to ensure a transparent and consistent engagement process between DHSC and the Devolved Governments to support the making of regulations under section 2 and 2A of HIAA.

8.2 Meetings will be held as early as possible during the process set out in Section B to agree how international obligations in areas of devolved competence should be implemented and determine a feasible timetable for all parties. This might include Ministers in the Devolved Governments making regulations or alternatively the Secretary of State making regulations on behalf of the Devolved Governments.

8.3 The Devolved Governments will notify DHSC how they wish to proceed in a timely manner to ensure obligations can be implemented by any agreed deadline in an international reciprocal healthcare agreement. DHSC do not intend to exercise section 2 powers to make regulations in areas of devolved competence without the agreement of the relevant Devolved Governments.

8.4 When making regulations in areas of devolved competence, officials and Ministers agree to share information, including draft regulations and proposed timetables, to ensure obligations in international agreements are implemented coherently and on time. The timetable for delivery of the regulations will be agreed in advance with the Devolved Governments. The Devolved Governments will notify the UK Government and each other of any potential impacts on the delivery timetable for example, minimum notification periods, legislative process/protocol and translation requirements. Drafted regulations will be shared in a timely manner to provide an opportunity for consideration and comment. Engagement must be as early as possible to allow time for ministerial and Parliamentary

consideration. Officials will collectively agree when to share a draft of the regulations to which HIAA applies with their respective Ministers.

8.5 Section 2A of the HIAA provides powers to the Devolved Governments to make regulations to implement reciprocal agreements in their respective countries if provision is within the devolved competence of the Devolved Government. If the UK Government has concerns about any delay in the implementation of international obligations, or the Devolved Governments fail to make regulations within the agreed timeframe, or in the event that agreement on the regulations cannot be reached, the process set out above (6. Dispute Resolution) will be followed. If no resolution is found, there will be an exchange of letters between Ministers. This would provide the opportunity for a Devolved Government to set out its position, and for the Secretary of State to explain the reasons for the final form of the regulations and how the UK Government has sought to reach agreement. If the Secretary of State decides to proceed without resolution and guided by the principles set out in this Memorandum, the exchange of letters will be made available to both Houses of Parliament and the Devolved Governments will bring them to the attention of their respective parliaments.

9. Operational Implementation

9.1 Before an agreement comes into force the Governments should demonstrate operational and communication readiness. Officials from all Governments commit to consult on and set out a timescale for implementation.

9.2 DHSC and the Devolved Governments will ensure a cooperative and coordinated approach to the operational implementation of reciprocal healthcare policy that works for all parts of the UK. This may for example include developing and coordinating bespoke packages of communications to inform individuals and healthcare providers about new reciprocal healthcare agreements.

9.3 All four Governments will work together, where appropriate, on matters of mutual interest to provide the most effective outcomes for citizens of the UK and promote equity of treatment across the UK. Various public bodies deal with reciprocal healthcare matters within the responsibilities both of the UK Government and the Devolved Governments. The UK Government and Devolved Governments affirm their commitment to work together, where appropriate, to ensure that such bodies continue to operate effectively.

10. Review

10.1 This Memorandum of Understanding will be reviewed no later than 24 months after the date it is agreed, with any subsequent reviews to be scheduled in the course of the review. This review will be conducted by officials and agreed by Ministers.

10.2 The Governments recognise that there may be a need from time to time for some adjustment to be made to the Memorandum of Understanding, for example, in response to new issues or in the light of any changes to concordats and bilateral relations more generally. The Governments agree that there should be mechanisms in place to review the operation of the settlements and for adjustments to be agreed.

D. DATA SHARING

To support ongoing collaboration between all parts of the UK, a separate Memorandum of Understanding will cover data sharing.

E. SIGNATORIES

Minister of State for Health, UK Government

Minister for Health and Social Services, Welsh Government

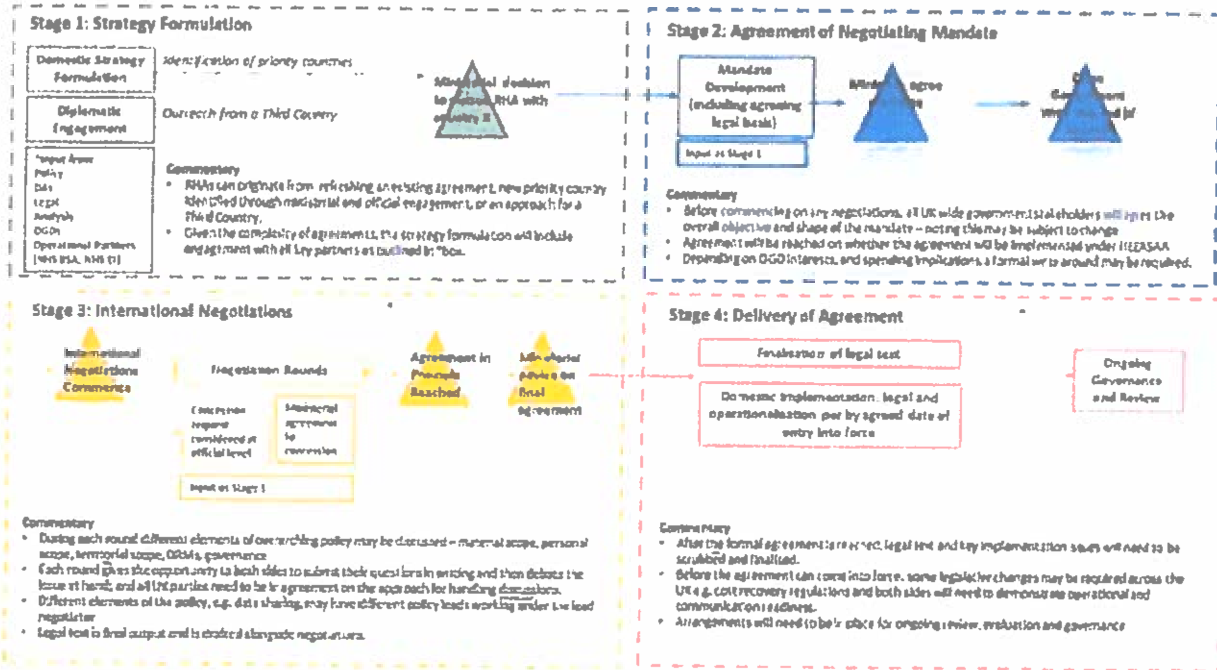
Cabinet Secretary for Health and Social Care, Scottish Government

Minister of Health, Northern Ireland Department of Health

ANNEX A

Reciprocal Healthcare International Negotiations Process Map

Reciprocal Healthcare International Negotiations Process Map



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

Llywodraeth Cymru
Welsh Government

Russell George MS
Chair,
Health and Social Care Committee

SeneddHealth@senedd.wales

7 June 2023

Dear Russell

I refer to my letter to you of 25 April 2023 and the letter of 2 June 2023 to Huw Irranca-Davies MS, Chair of the Legislation, Justice and Constitution Committee which was copied to you. I am writing to inform the Committee that the Secretary of State has laid the Healthcare (International Arrangements) (EU Exit) Regulations 2023 ("the HIA Regulations"). I have laid a Written Statement in this regard which can be found at: gen-ld15871-e.pdf (senedd.wales)

The Regulations were made by the Secretary of State, in exercise of the powers conferred by the Healthcare (International Arrangements) Act 2019.

The Statutory Instrument (SI) is subject to the affirmative procedure and was laid before Parliament on 5 June 2023.

I have written similarly to Huw Irranca-Davies MS.

Yours sincerely

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

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

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

Lynne Neagle AS/MS
Y Dirprwy Weinidog Iechyd Meddwl a Llesiant
Deputy Minister for Mental Health and Wellbeing

Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref MA/LN/0936/22

Russell George MS
Chair, Health, Social Care and Sport Committee
Welsh Parliament
Cardiff Bay
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CF99 1SN

07 June 2023

Dear Russell,

I am writing to provide you with an update on progress against the recommendations in the 'Everybody's Business' report which is attached at Annex A.

As the Committee will know, preventing suicide is a top priority for me. On 2nd March 2023 we hosted a National Conference on Preventing Suicide and Self Harm which took place at Cardiff City Hall. The conference, which was arranged by the NHS Collaborative in partnership with Welsh Government, Swansea University and Improvement Cymru was full to capacity. I was very pleased to speak at this important event to re-affirm our commitment to suicide and self-harm prevention in Wales. The event included a list of eminent speakers including Professor Ann John (Swansea University), Professor Louis Appleby (Professor of Psychiatry at the University of Manchester and Director of the National Confidential Inquiry into Suicide and Safety in Mental Health) Professor Rory O'Connor (Professor of Health Psychology at the University of Glasgow) and Dr Rosalind Reilly (Consultant in Public Health, Public Health Wales). Crucially, the speakers also included people with lived experience, and we were fortunate to be able to hear from Emma O'Sullivan, DPJ Foundation; Mental Health Farming Charity and Dr Simon Jones, Chair of the North Wales Suicide and Self Harm Prevention Forum. The event was an overwhelming success, and the conference report will be fundamental to informing our work to develop the successor to Talk 2 Me 2.

On 28 October 2022 we launched our draft guidance '*Responding to people bereaved, exposed or affected by suicide'.* The guidance was informed by insights into the needs and experiences of people living with bereavement by suicide in Wales, following a listening exercise that explored the points in their bereavement journey when they interface with statutory or voluntary services. The guidance aims to ensure services provide a more compassionate response.

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

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

The consultation ended on 20th January and 38 responses were received. The National Task and Finish Group for the guidance document has now re-convened following the closure of the consultation and will re-focus as an implementation group. This group will work to embrace the responses from the consultation into a revised document, for final publication, while also working on the implementation of the systems response described within it, continuing to work collaboratively with the relevant agencies, and with experts by experience.

Officials are also finalising the specification to commission the National Suicide Bereavement Liaison Service. This work has taken longer than anticipated due to data sharing issues, but I expect the procurement process to commence imminently.

Since our last update, the Cross Government Suicide Prevention Strategic Group has met on a further two occasions. The meeting in November 2022 focused on ensuring a joined-up response to the cost of living crisis as well as suicide prevention in schools and transport. The focus of the meeting on 17 April 2023 was on strengthening the multi-agency immediate response arrangements following a probable suicide.

As I reported in my last update to the Committee, we have now transformed the suicide and self-harm prevention infrastructure in Wales since the *Everybody's Business* Committee report. This transformation, along with development of the successor strategy and the continued work led by the national suicide prevention co-ordinator will deliver the key themes across the Committees recommendations. I would therefore like to assure you that the recommendations will continue to shape the work on suicide prevention and I would welcome a discussion with you about the format of future updates.

I would like to thank the Committee for its continued focus on suicide prevention and self-harm.

Yours sincerely

Lynne Neagle AS/MS
Y Dirprwy Weinidog Iechyd Meddwl a Llesiant
Deputy Minister for Mental Health and Wellbeing

Health, Social Care & Sport Committee - Everybody's Business
Welsh Government Status report on recommendations
Everybody's Business, a report on suicide prevention in Wales, December 2018

June 2023 Update

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
1	We recommend that a suicide prevention training framework should be adopted and implemented across all public services in a similar way to the framework for domestic violence, where training requirements are specified depending on the role. In particular, GPs would be one of the groups of professionals with greater training / skills requirements, and it is important that they and their practice staff have confidence to ask the right questions and respond compassionately and effectively when dealing with patients who may be at risk of suicide. We believe that the National Advisory Group should take this forward as an immediate priority, particularly given that a training framework	The work around universal suicide prevention training continues to evolve A digital platform is currently in development providing a 'suicide and self harm (SSH) Cymru training hub' to help front line workers to navigate what is a crowded market of training products and programmes in an informed way. It will also provide short-cuts to free on-line training videos and e-learning resources available across the UK There are also training frameworks available on the ACES AWARE Hub, and another being developed through Traumatic Stress Wales. It is possible that the digital training hub will expose gaps in training provision, as people seek products to suit their particular development needs. The National Coordinator is liaising with AGORED and Adult Learning Wales to look at developing specific units (curricular and learning outcomes) and potentially a national qualification.	We have now launched a digital HUB Welcome to the Suicide and self-harm Prevention Cymru Training Hub (sshp.wales) to assist workers from all sectors in accessing free and costed training and development offers relating to suicide and self harm prevention. We will now focus on raising awareness of the digital hub and identifying gaps in training provision. The future approach to training across all groups will be set out in the successors to Talk to Me 2 and Together for Mental Health This recommendation is now closed.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	has already been developed and is being launched in England		
2	We recommend that the Welsh Government should take the lead in promoting existing materials, such as the "See. Say. Signpost." training resource as part of a campaign to raise public awareness and embed the message that suicide is everybody's business and can happen in any community at any time.	In addition to the update provided in February 2021, please see the update to the previous recommendation. This work will continue in the course of 'business as usual' and further activity will be included within the routine National Co-ordinator updates made available to stakeholders. We will also continue discussions on how best to raise awareness through the work of the Cross Government Group on Suicide Prevention and through the work programme of the National Co-ordinator on Suicide and Self Harm.	Since the publication of Everybody's Business new chief officers have been appointed to lead agencies (Samaritans, MIND, PAPYRUS), and we continue to work with them around key messaging and engagement, and they all attend the National Advisory Group for suicide and self harm prevention. More recently, Samaritans have recruited a community engagement worker who now attends all three regional forums supporting this collaboration at a regional level. The coordinator team has produced a QR code to assist local teams and front-line workers in providing a link to the 2016 version of Help is at Hand Cymru on Dewis Cymru in both English and Welsh The document has also been uploaded onto the digital platform Help is at Hand Pages - NHS SSHP. This will enable the information to be continually updated, and to improve accessibility across different groups. This recommendation is now closed.
5	We recommend that the Welsh Government take urgent action to ensure that all	NICE is currently consulting on new guidance on self harm. Welsh Government will issue a Welsh Health Circular on decisions about	The NICE guidance on self harm was published on 7th September 2022: Overview | Self-harm: assessment, management and

Pack Page 95

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	GPs in Wales are aware of and understand the GMC guidelines on sharing information and the consensus statement agreed by the UK Department of Health, Royal Colleges and other partners. We support the campaign by Papyrus to encourage chief executives of NHS bodies to provide assurance that they will support staff who make a best interest decision to break patient confidentiality in order to protect life	confidentiality rights when supporting patients who are considered at risk of suicide or self-harm following the publication of the NICE guidance later this year.	preventing recurrence | Guidance | NICE. . Officials have recently issued a Welsh Health Circular to draw attention and raise awareness of the guidance across NHS, including primary care. Officials have also recently issued a Welsh Health Circular on Information disclosure in relation to confidentiality rights. This recommendation is now closed.
6	We recommend that the Welsh Government must take all necessary steps to ensure parity between mental and physical health services. This should be tied to "A Healthier Wales", and the Welsh Government must ensure that its plans for the development of health and social care services give the same priority to mental health and wellbeing as to physical health. This includes ensuring the allocation of appropriate resources, and that patient outcomes, in terms of improved mental health, are	Ensuring parity between physical and mental health is firmly embedded in health strategies in Wales and the Programme for Government makes a commitment to continue to prioritise investment in mental health. On this basis, this element of the recommendation in closed. In terms of outcome measures for mental health, training and resources to embed the use of patient reported outcome and experience measures in all mental health teams in Wales began in June 2021 and this work will continue to be supported until March 2023. This work is now being taken through the Mental Health Data and Outcomes Measures Board which reports to the Together for Mental Health Ministerial Oversight Board.	Representatives of over 80% of the mental health and learning disability teams in Wales have now received training in how to embed patient reported outcome and experience measures into day to day practice. Significant resources have been developed to support the outcomes work and these are all available on the Outcome Measures The feedback on the training has been very positive, however the impact of the pandemic on capacity to translate training into consistent practice has been variable. As a result, we are extending the project by a further year to provide additional support to health boards. Enabling service users to describe what is important to them, having

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	measured and reported. If the Welsh Government is serious about achieving parity between mental and physical health, it must consider whether the introduction of meaningful targets would ensure health boards give sufficient focus to improving mental health services and patients' experience of care		goals and aspirations is key to providing effective, safe and compassionate care. This work continues to be taken through the Mental Health Data and Outcomes Measures Board which reports to the Together for Mental Health Ministerial Oversight Board.
8	We recommend that the Welsh Government develops an all-Wales triage model which would see community psychiatric nurses based in police control rooms. We believe this work should be carried out in line with the six month timescale set out in the Children, Young People and Education Committee's Mind Over Matter report (its recommendation 15): ▪ That the Welsh Government, within six months of this report's publication, in relation to crisis and out-of-hours care: ▪ work with Welsh police forces to scope an all-Wales triage model which would see mental health practitioners situated in	As previously referenced, we committed £6million to improve crisis services in 2021/22 and we are making good progress in rolling out 24/7 access to urgent mental health support via 111. Our planned implementation for April has been impacted by the pandemic and challenges remain for health boards in the recruitment of key staff. Health boards are at different phases of implementation and we are aiming for 24/7 coverage across Wales by the end of the year – with some health board on track to have the service in place before the summer. Once fully implemented, the service will provide a direct line for police officers to call to request advice. Health boards are working locally with police forces where there are existing triage models in place. Continuing the transformation of crisis services is a priority for the additional mental health funding that we have secured for 2022/23. Funding will be directed to support the	The roll-out of 111 press 2 for Urgent Mental Health continues and six health boards have implemented the service on a 24/7 basis. Powys Teaching Health Board has implemented the service and it working towards 24/7 coverage by June. The service will also provide a contact line for professionals to call if they need to access advice and support for an individual that they are concerned about. This service has been welcomed by a number of groups that already using it, for instance the police and social workers.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	police control rooms to provide advice when children and young people (and other age groups, if appropriate) present in crisis; ▪ outline how resources could be directed towards enabling crisis teams in all health boards to provide training and cascade expertise to other frontline services, particularly colleagues in A&E, in border areas (to improve cross-border relations with those centres most often accessed by Welsh domiciled patients), and in schools (to normalise conversations about suicide and self-harm in particular); ▪ ensure that follow-up support is being provided by health boards after discharge, provide information on how health boards monitor this provision, and commit to making this information publicly available to ensure transparency and accountability ensure that all health boards are adhering to the requirement to hold designated beds that could be staffed adequately for unders-	improvements recommending by the NHS Delivery Unit following its review of crisis care. Health boards submitted plans for this funding at the end of May and officials are considering the bids. We also continue to pilot the mental health conveyance service with St John Cymru. This pilot has received positive feedback from stakeholders, particularly from Approved Mental Health Practitioners and the Police. Plans are in place to roll-out the service following the successful pilot period Welsh Government commissioned the NCCU to undertake a review of designated bed usage in 2021. The NCCU and the NHS Delivery Unit are now developing updated guidance with more regular data capture to support improvements. Guidance on the delivery of liaison psychiatry services (LPS) in Wales was published in December 2021. This document provides guidance on the functions of Liaison Psychiatry Services (LPS) in Wales. It has been developed in conjunction with key stakeholders throughout Wales and all professional groups have been represented. This guidance applies across the age range and whilst differentiation may be needed, no age range should receive services of a lesser quality. Service user and carers' voices have been sought and are reflected in this document. It contains eight standards to	

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	18s in crises, indicating how this will be monitored and reported in future, and what steps will be taken if such beds are not available; ▪ implement with pace and in a uniform way across health boards the single point of access approach to specialist services, to ensure timely and appropriate access to support, urgent or otherwise; and ▪ reflecting on the results of the review of crisis care, outline what more needs to be done to deliver a safe and cost-effective 24/7 crisis care service in all areas of Wales, how that will be done, and by when.	support equitable access to and provision of LPS in Wales and reflect both The National Institute for Health and Care Excellence (NICE) and professional body standards. Collecting information in relation to the standards will assist health boards to develop a clear picture of service demand, uptake and delivery. It is expected that both qualitative and quantitative information will become available as services develop and mature. Auditing information about the LPS should enable health boards to make evidenced-based decisions about the future provision of that service. Psychiatric Liaison Services has also been made a priority within this years' service improvement funding.	

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
9	We recommend that the Welsh Government takes urgent action to establish to what extent those discharged from inpatient care are currently receiving follow-up care within the targeted timescale and provide an update to the Committee within three months. This should include steps to ensure that IT systems can identify whether this is happening	This continues to be progressed through the work of the Mental Health Data and Outcomes Measures Board. The draft core mental health dataset has been circulated to health boards to impact test and to understand which elements are already recorded by health boards and which elements would need to be added. This has helped identify any elements which would be difficult to record. The report on this impact testing has now been received by the NHS Collaborative. The core data was submitted to the Welsh Information Standards Board in July as part of the approval process. Alongside the outcomes training referenced in recommendation 6, the University of South. Wales has been commissioned to work with health boards and other stakeholders to develop outcome measures for mental health services. The initial mapping work report is due by Summer 2022.	To further support this work a Technical Group has been set up and reports to the Mental Health Outcome and Measures Board. This group comprises of health board digital/performance leads and is focusing on the practicalities of collecting and sharing data. It is recognised that establishing a full dataset is complex and we are prioritising specific data items at each stage to ensure that any data collected is robust and fit for purpose, with the initial focus being on referrals and admissions data. We will also be prioritising demographic data, such as age, gender and ethnicity which will support our ability to plan services based on the needs and demands of our population. We understand the need to have data publicly available as soon as practicable and we are working towards having an initial national dashboard on mental health activity available by September, we will then broaden this available data incrementally as the core
10	We recommend that the Welsh Government introduces six monthly monitoring and reporting of the target in the Together for Mental Health Delivery Plan that all patients discharged from inpatient care receive follow up care within the specified timescale		
11	We recommend that, in light of the evidence that suicide risk		

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	is greatest on the third day after discharge, the target for patients discharged from inpatient mental health care to receive a first follow-up appointment should be changed to ensure that patients are followed up within 48 hours		dataset evolves. By December, we will also collect an agreed set of patient experience measures nationally This work is informed by the University of South Wales commissioned work that aimed to understand what is important to people in relation to outcomes from mental health services. The work stream is currently linking with other NHS programmes that will support the publication of national mental health outcomes and with colleagues in the Nursing Directorate to support the development of experience measures. As part of the NHS Executive remit letter, we have confirmed that the Executive will deliver a national safety programme for mental health services. This will have an initial focus on inpatient settings and will include discharge arrangements.
12	We recommend that a target be introduced for waiting times for psychological therapies to ensure that those in need receive this support within a suitable timescale. Accessing appropriate therapy early can provide the intervention that's needed and prevent someone from requiring crisis care at a later stage	We remain committed to publish waiting time data on specialist psychological therapies, but this work has been delayed during the pandemic. Whilst the data is not yet robust enough to publish, operational data is reported by all health boards and used by the Welsh Government to hold services to account. The NHS Delivery Unit has been commissioned to undertake a review of psychological therapies to understand the consistency and variation in services and data reporting across health boards.	We continue to use the operational data that is reported by all health boards to hold services to account through monthly Improvement, Quality, Performance and Delivery meetings. The NHS Delivery Unit's review of psychological therapies is due for completion in May and we will use this work to inform the publication of the data thereafter. This work will also inform the development work for the mental health core dataset that will ensure that we are able to reflect a fuller picture of provision across Wales.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
		The waiting time data that will be published only reflects one element of access to psychological therapies – the specialist services. Data is already published for Local Primary Mental Health Services, which includes psychological therapies and we have strengthened low level support, for instance through the introduction of online Cognitive Behavioural Therapy – another form of psychological therapy. The work to develop the mental health core dataset will ensure that we are able to reflect a fuller picture of provision across Wales. We are working with HEIW and Improvement Cymru to continue to develop the infrastructure to support health boards to improve access to psychological therapies. This work will ensure that we have a robust process to consider the evidence base of interventions that underpin Matrics Cymru and Matrics Plant. Matrics Plant Implementation Plan was published in September 2021.This plan has been designed to support the implementation of Matrics Plant: Guidance on the Delivery of Psychological Interventions for Children and Young People in Wales. It is anticipated that it will assist health boards and partners in ensuring that both the spirit and detail of Matrics Plant are transferred into action.	The first revision of the Evidence tables published in 2021 to ensure psychological interventions are safe and effective has been further revised and it is anticipated a second revision will be published by spring 2023. Guidance for improving access to, and the effectiveness of psychological interventions for people from Black, Asian and minority ethnic communities has been commissioned and will be published in spring/summer 2023. A review of the evidence for psychological approaches aimed at reducing emotional regulation difficulties in adults and children and young people accessing help for their mental health is also underway. We continue to work with HEIW to develop the infrastructure around psychological therapies in Wales. This includes funding a professional lead post to drive this work forward. It is envisaged that this post will shortly be out to recruitment.
13	We recommend that the Welsh Government accepts	Informed by the insights gained from the listening exercise conducted in 2020/21 with	The Real Time Suicide Surveillance System in Wales, launched in April 2022, continues to

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	the call made in the mid-point review of Talk to me 2 to develop and implement a Wales-wide postvention strategy for suicide, and that this work should be taken forward as an immediate priority. This should include details of follow up support for individuals bereaved by suicide, and in organisational settings. It should incorporate the recommendation in Mind over matter that guidance should be issued to all schools on talking about suicide (and as a priority, to schools where there has been a suicide or suspected suicide). The Welsh Government should ensure that sufficient ring-fenced resource is available to implement this postvention strategy.	those living with bereavement by suicide, a multi-agency task and finish group has been meeting to set out guidance for a Wales-wide response to those exposed, affected or bereaved by a sudden death that could be a possible suicide (rapid response would mean pre-inquest). This has included mortuary staff, coroners office, funeral directors, primary care, suicide bereavement support agencies, blue-light and rescue services. The Real Time Surveillance System will provide information to help services to ensure that those bereaved by suicide are offered timely and appropriate support. A draft guidance document is now out for wider review. A key recommendation of this work is the provision of a National Bereavement Liaison Service to make a proactive offer of support following a suspected suicide. Officials are exploring options to develop or commission this support. Guidance on talking about suicide was provided to all schools following publication in September 2019. Officials in the Welsh Government are in the process of developing proposals to review awareness in schools and are considering what further support is needed in this space.	provide crucial information to help strengthen our preventative work, to ensure support is made available quickly and to identify trends or clusters. We launched our draft consultation guidance document 'Responding to people bereaved or affected by suicide in Wales on 28th October 2022. The consultation ended on 20th January 2023 and 38 responses were received. Officials are currently reviewing the responses. The Guidance will be supported by a new Suicide Bereavement Liaison Service later this year. The Service will aim to ensure a consistent, timely, and proactive offer of support to people affected by sudden deaths that are unexplained or a suspected suicide. As part of a review of our published guidance on suicide and self-harm awareness in schools (2019), officials are in the process of organising an event and other focused research to take the view of educators on how to facilitate safe communication around suicide and self-harm prevention and postvention in education settings. This will inform research for updating the guidance for schools, and will assist with identifying what support schools need when they encounter issues of suicide and self-harm in the classroom.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
14	We recommend that the Welsh Government and Public Health Wales actively promote the availability of the Help is at Hand Cymru resource. This should include proactively engaging with third sector support groups and ensuring that frontline staff, particularly emergency services, who have contact with those bereaved by suicide are not only fully aware of Help is at Hand Cymru but, crucially, have access to copies of the resource so that this can be distributed to those bereaved at the point of need. As this resource is already available, this should be implemented within 3 months	The digital supplier developing the training hub will be supporting the development of a digital version of Help is at Hand, which will provide an opportunity to review the content, update the signposting to services and resources in Wales, and to consider other ways of making the content available. This will be available in Autumn 2022. While this is being developed a 'business card' with a QR Code to the current version on the Dewis Cymru website is being printed to make available to front-line responders across Wales The same QR Code will be able to take people to the new digital version when it becomes available	The National and Regional Suicide and Self-Harm Co-ordinators have produced a QR code to assist local teams and front-line workers to easily access the Help is at Hand resources in Dewis Cymru in both English and Welsh The document has also now been uploaded onto a digital platform Help is at Hand Pages - NHS SSHP Additionally, as referenced in Recommendation 13, our draft guidance document 'Responding to people bereaved or affected by suicide in Wales' will be supported by a new Suicide Bereavement Liaison Service later this year. The Service will aim to ensure a consistent, timely, and proactive offer of support to people affected by sudden deaths that are unexplained or a suspected suicide. This recommendation is now closed.
15	We recommend that the Welsh Government should, as part of an all-Wales postvention pathway, give active consideration to providing funding for support	See 'National Bereavement Liaison Service' information in recommendation 13. Is this correct – did we say this last time.	See 'National Bereavement Liaison Service' information in recommendation 13.

Pack Page 104

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	groups for those bereaved by suicide, so that people across Wales are able to access much-needed support. We believe such groups can play a key role in supporting the mental health and wellbeing of those bereaved through suicide. This could in turn lead to reduced demand for NHS services		
17	We recommend that the Welsh Government works with NHS employers in Wales to ensure that all employees who have dealt with cases of suicide/attempted suicide are able to access appropriate support	We expect all health boards to provide appropriate support to all staff following traumatic events. Health for Health Professionals has been renamed 'Canopi' and provides mental health support to health and social care staff. This includes support for post-traumatic stress. This work is ongoing, and the National Coordinator is in conversation with the Royal College of Psychiatrists regarding the management of vicarious trauma, but also how we can prepare staff for inquests, for example. We are also signposting to the First Hand resource Home - First Hand (first-hand.org.uk) that supports those affected by the suicide of someone they didn't know	The National Suicide and Self-Harm Coordinator has linked with Canopi and presented at their national symposium at Cardiff University. Further engagement will continue to raise awareness of the suicide and self harm prevention support and information that is available. We continue to expect all health boards to provide appropriate support to all staff following traumatic events. This recommendation is now closed.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
18	We recommend that the Welsh Government recognise male suicide as a national priority and allocate appropriate funding to identify and implement new approaches to reducing the stigma associated with mental health to encourage men to talk about and seek help. This should include scope to roll out existing projects more widely	Preventing Suicide is a priority for the Welsh Government and a new cross-Government Group has been established to strengthen the approach. We have also committed additional funding for suicide prevention in 2022-23. We have recently established the Real Time Suicide Surveillance system in Wales, This will provide more timely access to information from all probable suicides (including male suicides) to identify opportunities for prevention and to ensure appropriate support is provided. As part of our programme to review and develop a successor strategy to Talk to Me too, we will be engaging with key stakeholders and reviewing the evidence to ensure new actions are evidenced based. Given the prevalence of suicide for middle aged men, we would expect this to be a key area of focus. We are also working with our National Suicide Coordinator to agree a programme of work to review the evidence of suicide prevention programmes and intervention with a focus on middle aged men. This work will continue in the course of 'business as usual'.	Preventing suicide remains a priority and the additional funding for suicide prevention in 2022-23 has been made available to the programme on a recurring basis. The Real Time Suicide Surveillance System in Wales, launched in April 2022, will provide crucial information to help strengthen our preventative work, to ensure support is made available quickly and to identify trends or clusters. As per the previous update, as part of our programme to review and develop a successor strategy to Talk to Me too, we will be engaging with key stakeholders and reviewing the evidence to ensure new actions are evidenced based. Given the prevalence of suicide for middle aged men, we would expect this to be a key area of focus. To ensure the approach is targeted, we will be analysing ONS data and data from the Real Time Suicide Surveillance System to identify at risk groups. This work will continue in the course of 'business as usual' and through the development of the new strategies.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
19	We endorse the recommendation of the mid-point review of Talk to me 2 that the implementation of NICE guidance on self-harm be a priority for the Welsh Government. This should be implemented within 6 months of the publication of this report	A workshop was held in February 2022 to raise the profile of the new NICE Guidance for the assessment and management of self-harm that was out for consultation at that time. The Guidance is expected to be published later this year when a further workshop will be held for those identified as key agencies for implementation, to explore opportunities and barriers and to inform how we support front-line workers to work to the guidance	The revised NICE guidance (assessment, management, and preventing recurrent for children, young people, and adults who have self harmed) was published in September 2022. A workshop on the guidance took place at the National Conference for suicide and self harm prevention on 2nd March 2023, with Prof Nav Kapoor who was on the NICE committee, in attendance. Headlines from the conference will be shared on the digital hub for suicide and self harm prevention in Wales The revised guidance reaches out to professionals beyond the health service or mental health (eg: staff in education settings, third sector organisations, and the criminal justice system) and further work is required to determine how NICE compliance can be supported across multi-agency pathways for people affected by self harm
24	We recommend that the Welsh Government ensures that the Children, Young People and Education Committee's Mind Over Matter recommendations are implemented in order to improve and protect the mental health and wellbeing of children and young people in	Further activity in response to this action will be reported in updates against the Mind Over Matter recommendations.	Further activity in response to this action will be reported in updates against the Mind Over Matter recommendations.

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	Wales. On suicide specifically, we recommend that the Mind Over Matter recommendation on guidance to schools (its recommendation 16) should be taken forward as an immediate priority: That the Welsh Government, in relation to suicide specifically, work with expert organisations to: ▪ provide, within three months of this report's publication, guidance to schools on talking about suicide and self-harm, to dispel the myth that any discussion will lead to "contagion"; ▪ work with expert organisations to prioritise the issuing of guidance to schools where there has been a suicide or suspected suicide; and ▪ ensure that basic mental health training, including how to talk about suicide, becomes part of initial teacher training and continuous professional development, so that all teachers are equipped to talk about it		
31	We recommend that the Welsh Government / other	A new, cross-Government Suicide Prevention Strategic Group has been convened to	The additional and recurrent funding for suicide prevention has significantly

Pack Page 108

	Recommendation	Welsh Government Update August 2022	Welsh Government Update June 2023
	public bodies (LHBs / LAs) make specific funding available for suicide prevention to ensure that it is sustainable in the long term. The Welsh Government should work with the National Advisory Group to ascertain how much funding is needed to ensure this sustainability, and ring-fence the appropriate amount	strengthen the programme management arrangements for the suicide prevention work programme. This will include driving work across Government and prioritising investment to support this approach. Additional, recurrent funding has been allocated to the suicide prevention work programme in 2022/23. In particular, the new funding will support the newly established Real Time Suicide Surveillance System in Wales launched in April 2022 and to improve suicide bereavement support. Additionally, the wider service transformation also has a focus on preventing suicide – for instance the work to improve crisis care and the establishment of the 111 mental health single points of contact. Talk to me 2 is currently being externally evaluated and the findings from which will inform any appropriate next steps.	strengthened the infrastructure in Wales. This includes the National Suicide and Self-Harm Prevention Co-ordinator and Regional Co-ordinators, the establishment of the Real Time Surveillance System with analytical resource and the soon to be commissioned National Suicide Bereavement Family Liaison Service. This will ensure dedicated resource and stability for suicide and self-harm going forwards. This recommendation is now closed.

HOUSE OF LORDS
Secondary Legislation Scrutiny Committee

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6 June 2023

Russell George MS
Chair, Health and Social Care Committee
Senedd Cymru

Dear Russell

Health Service Procurement (Wales) Bill

Thank you for your letter of 24 May 2023 drawing the Secondary Legislation Scrutiny Committee's attention to this legislation. The Committee will be very grateful for the information offered by your Stage 1 report when, in due course, considering any procurement regulations brought forward by the UK Government.

May I also take this opportunity to reassure you that, when considering regulations laid before Parliament, this Committee always keeps a watchful eye on cross-border issues that may impact the Devolved Administrations.

Yours ever

David

Rt Hon. the Lord Hunt of Wirral MBE

Chair of the Secondary Legislation Scrutiny Committee

Y Pwyllgor Iechyd a Gofal Cymdeithasol

—

Health and Social Care Committee

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Sue Tranka
Chief Nursing Officer for Wales

31 May 2023

Dear Sue

Nurse Staffing Levels (Wales) Act 2016: post-legislative scrutiny

As you may be aware, the Health and Social Care Committee recently announced a post-legislative scrutiny inquiry into the Nurse Staffing Levels (Wales) Act 2016. Details of the terms of reference for the inquiry are available on our website.

We are currently gathering written evidence, and plan to hold oral evidence sessions with stakeholders later this year. We will also be issuing an invitation to you and the Minister for Health and Social Services to attend an oral evidence session in due course.

In the meantime, we would be grateful if you could provide the following information:

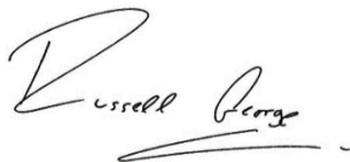
1. A copy of, or link to, the evidence-based workforce planning tools described in paragraph 41 of the Nurse Staffing Levels (Wales) Act 2016 statutory guidance (version 2) published in March 2021.

   If it is not possible to provide us with copies of, or links to, these tools, please provide screenshots of the tools and/or a full description of how the tools work.

2. A copy of the operational guidance on the use of the tools described in paragraph 43 of the statutory guidance.

To enable us to consider this information as we prepare to take evidence from stakeholders, we would be grateful to receive it by Friday 15 July 2023.

Yours sincerely



Russell George MS
Chair, Health and Social Care Committee

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

Nursing & Midwifery Council

Russell George MS
Chair, Health and Social Care Committee
Senedd Health,
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By email: SeneddHealth@senedd.wales

16 May 2023

Dear Mr George,

I am writing to share the Nursing and Midwifery Council's (NMC) response to the Department of Health and Social Care's (DHSC's) consultation, concerning draft legislation for regulating anaesthesia associates (AAs) and physician associates (PAs). This draft Order will also form a template for replacing the existing legislation that sets out how other health and care professionals are regulated, including nurses and midwives registered with the NMC.

The draft Order marks the next step in introducing positive change to our legislation. We have long called for this change because our legislation, written in 2001, has failed to keep pace with changes in society and nursing and midwifery practice.

In our role as the regulator of almost 39,000 nursing and midwifery professionals in Wales, and more than 771,000 professionals across the UK, it is vital we have the tools available to regulate well. Through regulatory reform, we hope to have more modern, flexible legislation that better enables us to protect the public we serve, and support the professionals who are at the core of Welsh health and care services.

The draft AAPA Order provides a clearer, more coherent approach to regulation. It largely aligns with our aspirations for regulatory reform and would provide us with the flexibility to pursue further improvements.

However, certain key functions outlined in the draft legislation require greater clarity, while others remain unduly restrictive. In parts, the drafting is overly complicated and could lead to confusion, ambiguity and some of the central benefits of the proposed reforms remaining out of reach.

The AAPA Order consultation document indicates that the DHSC plans to begin working with us, alongside the General Medical Council and Health and Care Professions Council, to develop a subsequent set of legislation to replace our existing frameworks.

We look forward to working with the DHSC and our partners to make sure these reforms enable us to better support nurses and midwives to provide safe and effective care to people and communities.

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We're the independent regulator for nurses and midwives in the UK, and nursing associates in England.
Our vision is safe, effective and kind nursing and midwifery practice that improves everyone's health and wellbeing.

Registered charity in England and Wales (1091434) and in Scotland (SC038362)

We will be back in touch with you in due course to notify you of next steps for our engagement on this reform programme.

If you have any questions in the meantime, please contact public.affairs@nmc-uk.org.

Yours sincerely,

Matthew McClelland
Executive Director of Strategy and Insight

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Health and Social Care Committee
Welsh Parliament
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Letter sent via email to: SeneddHealth@senedd.wales

Date: 16/05/2023

Dear Health & Social Care Committee,

I am writing to you to inform your ongoing work monitoring progress towards the ambitions set out in the Welsh Government's plan for transforming and modernising planned care.

RNIB Cymru is concerned that the waiting list reduction targets outlined in the plan fail to account for clinical prioritisation targets. As a result, there is a lack of political attention and scrutiny on publicly available clinical prioritisation targets such as the Eye Care Measures for NHS outpatients.

Health boards do not appear to be being held accountable for meeting these targets, which is allowing for clinically inappropriate decision making and negative outcomes for patients.

Background

In 2019 the Welsh Government introduced the **Eye Care Measures for NHS Outpatients in Wales (ECM)** after concerns were raised that Ophthalmology services across Wales were struggling to manage key issues around capacity and demand. Patients were waiting far too long from initial referral from primary care to follow-up assessment and treatment. This caused significant numbers of patients with treatable conditions to permanently lose their sight.

Wales was the first country in the UK to introduce these dedicated clinical prioritisation targets for Ophthalmology. Introduction of the ECM aimed to shift the focus away from traditional RTT targets in favour of a more prudent approach to waiting list management and clinical prioritisation. Unlike RTT, the ECM allows for clinical capacity to be directed to the most clinically urgent cases to ensure that patients with the highest levels of risk associated with their condition are treated in a safe and clinically appropriate timeframe.

This is critical for Ophthalmology because a significant number of patients need to be seen much sooner than the 26 week RTT target in order to mitigate the risk of irreversible harm or blindness. Under the ECM system, all new and follow-up patients are allocated a Health Risk Factor based on their clinical need and given an individualised target date for when they should be seen. HRF categorisations are as follows:

R1 – risk of irreversible harm or significant patient adverse outcome if target date is missed.
R2 – risk of reversible harm or adverse outcome if target date is missed.
R3 – no risk of significant harm or adverse outcome.

Each month the Welsh Government publish statistics on the number and percentage of attendances for those patients assessed as being at risk of irreversible harm or significant adverse outcome should their target date be missed (R1). **In short, patients categorised as R1 are at real risk of going blind or suffering significant, irreversible sight loss if their treatment is delayed.**

What does the latest ECM data show?

Latest available ECM data for February 2023 shows that less than half of the 138,646 patients (48.6 per cent) categorised as being at the

highest risk of irreversible harm (R1) were seen within their clinically safe target date.

This means that over 71,000 people in Wales are waiting too long for treatment and are at risk of preventable sight loss.

Since July 2020, there has not been a single month when over half of R1 patients have been seen within their clinically safe target date.

What is being done?

Plan for transforming and modernising planned care and reducing waiting list targets

The waiting list reduction targets set by the Welsh Government's that are relevant to Ophthalmology are:

- No one waiting longer than a year for their first outpatient appointment by the end of 2022.
- Eliminate the number of people waiting longer than two years in most specialities by March 2023.
- Eliminate the number of people waiting longer than one year in most specialities by Spring 2025.

These targets focus entirely on the length of time people wait for an initial appointment but do not focus on clinical prioritisation or on follow up treatments that are necessary to save people's sight. This means there is no political imperative to prioritise people who are at risk of irreversible sight loss over those with less urgent conditions which are quicker to treat and therefore make a greater impact against government waiting list targets.

We have been made aware that decisions are being made in some health boards which are clinically inappropriate. For example, redeploying Ophthalmologists from Age-related Macular Degeneration (AMD) injection clinics in order to treat lower risk but quicker to treat conditions like cataracts. The decision to prioritise cataract treatment over AMD is completely at odds with the clinical prioritisation agenda that the ECM were brought in to embed.

AMD is a condition that can cause irreversible harm to patients if they wait beyond their target date for treatment. Patients with Wet AMD can

experience rapidly progressing, permanent sight loss over the course of weeks or even days. Patients on the AMD pathway require regular treatments to ensure they maintain their sight and are therefore categorised as R1. In contrast, Cataracts are a condition that can cause harm but once treated the adverse effects are able to be reversed. Cataract pathways are therefore categorised as R2. Cataracts, however, are much quicker to treat than AMD.

Optometry reform

The Welsh Government has begun work on an ambitious programme of reform of Optometry services. Community-based optometrists will play a greater role in eye health treatment, diagnosis and aftercare. This will help to free up the capacity of Ophthalmologists to focus on the treatment of blinding eye disease that only they can treat. RNIB Cymru welcomes this initiative, but full implementation will take a number of years and patients continue to be at risk of avoidable, permanent sight loss.

Optometry reform will not solve this crisis in and of itself. Demand for hospital eye care services is far outstripping capacity. Eye health care services are some of the busiest in Wales with hospital ophthalmology clinics seeing 10 per cent of all outpatient appointments - and this is expected to increase by 40 per cent in the next 20 years.[1]

HBs will still need sufficient Ophthalmic capacity in secondary care to treat patients most at risk of avoidable sight loss. Only radical transformation of Eye Care service in Wales will stop patients from going blind unnecessarily. Ultimately, only Ophthalmologists can perform sight saving treatments and there is no plan in place to solve the urgent workforce shortage in secondary care.

Independent Review of Eye Care Services in Wales

An independent review commissioned by the Royal College of Ophthalmologists in 2021 described the staffing situation in certain health boards as “extremely serious” and “very fragile”.[2] The Royal College of Ophthalmologists advises that there should be 3.0 and 3.5 Consultant Ophthalmologists per 100 000 population. In England the reality varies between the best case of 3.1 in London, and 1.8 in the East of England. For Wales the number is 1.8.

[1] RNIB (2022) Sight Loss Data Tool

[2] Andrew Pyott (2021), External Review of Eye Care Services in Wales (rcophth.ac.uk)

The report recommended the establishment of three regional centres of excellence across Wales. These centres would encourage new recruitment and allow for Ophthalmic capacity, expertise, and technologies to be pooled to ensure an efficient and sustainable service. Each centre would deliver specialist visiting services in surrounding areas to enable people with conditions that require frequent treatments to access these closer to home.

Work is underway within Welsh Government to consider the recommendations of this report and the future of Eye Care Services in Wales. The report is due at the later end of the year. However, there has been no public Ministerial commitment to transformation and there are still no plans in place for reducing the numbers of people at risk of avoidable sight loss waiting beyond their target date in the **short, medium or long term.**

Four years since the ECM were first introduced, increasing numbers of people in Wales are still needlessly losing their sight whilst waiting for NHS treatment.

Radical action must be taken now.

Summary

We ask that the Committee consider these issues when undertaking analysis and scrutiny of the Welsh Government's waiting list reduction plan and when developing its termly monitoring reports.

In addition, we would be grateful if you would ask the Minister for Health and Social Services how they will ensure high quality, sustainable eyecare services that drive progress against the ECM. Plans must address capacity and workforce challenges and include timescales and targets for reducing the numbers of patients waiting beyond their clinically safe target date. They should also set out how principles for treatment and prioritisation of high-risk patients can be embedded into clinical decision making and waiting list management.

We would be happy to meet with the Committee or with individual Members to discuss any of these issues in more detail.

Kind regards

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Y Dirprwy Weinidog Iechyd Meddwl a Llesiant
Deputy Minister for Mental Health and Wellbeing

Llywodraeth Cymru
Welsh Government

Russell George MS,
Chair, Health and Social Care Committee
Welsh Parliament
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08 June 2023

Dear Russell

You will be aware that I consulted last summer on exploring proposals relating to supporting a healthier food environment in Wales. I published a summary of the findings in January Healthy Food Environment –Summary of Responses, where we received extensive engagement across the public, organisations and with the food industry. I now intend to deliver an oral statement on 27 June which will outline the Welsh Government position in relation to price promotions and locations.

I am writing to give you early notification of my intention to deliver an oral statement to the Senedd, and to bring forward subordinate legislation in 2024. I am happy to engage with you and the Committee around the statement and would welcome your views on what engagement would be of use to you and other members to support your scrutiny work.

I look forward to hearing your views following the statement and working together on this important area.

I have also sent a letter to the Chair of the Children and Young People's Committee and the Chair of the Legislation, Justice and Constitution Committee.

Yours sincerely,

Lynne Neagle AS/MS
Y Dirprwy Weinidog Iechyd Meddwl a Llesiant
Deputy Minister for Mental Health and Wellbeing

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

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