

Agenda – Health and Social Care Committee

Meeting Venue:	For further information contact:
Hybrid – Committee room 5 Ty Hywel and video conference via Zoom	Helen Finlayson Committee Clerk
Meeting date: 10 February 2022	0300 200 6565
Meeting time: 09.00	SeneddHealth@senedd.wales

In accordance with Standing Order 34.19, the Chair has determined that the public are excluded from the Committee's meeting in order to protect public health. This meeting will be broadcast live on www.senedd.tv

Private pre-meeting (09.00 – 09.30)

1 Introductions, apologies, substitutions and declarations of interest

(09.30)

2 Hospital discharge and its impact on patient flow through hospitals: evidence session with local authorities

(09.30–10.30)

(Pages 1 – 44)

Nicola Stubbins, Immediate Past President of ADSS Cymru and Director of Social Services – Denbighshire County Council

Councillor Susan Elsmore, Welsh Local Government Association Deputy Spokesperson for Health and Social Care and Cabinet Member for Social Care, Health and Wellbeing – Cardiff Council

Allison Hulmes, National Director Wales, British Association of Social Workers

Research brief

Paper 1 – Welsh Local Government Association and the Association of Directors of Social Services Cymru

Paper 2 – British Association of Social Workers



Break (10.30–10.45)

3 Hospital discharge and its impact on patient flow through hospitals: evidence session with Care Forum Wales

(10.45–11.30)

(Pages 45 – 46)

Mary Wimbury, Chief Executive – Care Forum Wales

Mario Kreft, Chair – Care Forum Wales

Sanjiv Joshi, Treasurer – Care Forum Wales

Paper 3 – Care Forum Wales

4 Paper(s) to note

(11.30)

4.1 Response from the Minister for Health and Social Services to the reports of the Health and Social Care Committee and the Legislation, Justice and Constitution Committee on the Legislative Consent Memorandum for the Health and Care Bill

(Pages 47 – 65)

5 Motion under Standing Order 17.42(ix) to resolve to exclude the public from items 6, 8, 9 and 10 of today's meeting

(11.30)

6 Hospital discharge and its impact on patient flow through hospitals: consideration of evidence

(11.30–11.45)

Lunch (11.45–12.30)

7 Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment and Scrutiny of the Welsh

Government's Health and Social Care Winter Plan 2021 to 2022: evidence session with the Minister for Health and Social Services

(12.30–14.45)

(Pages 66 – 165)

Eluned Morgan MS, Minister for Health and Social Services

Judith Paget, Director General for Health and Social Services and Chief
Executive of NHS Wales – Welsh Government

Andrew Sallows, Delivery Programme Director – Welsh Government

Chris Jones, Deputy Chief Medical Officer – Welsh Government

Research brief

Paper 4 – Welsh Government on waiting times

Paper 5 – Welsh Government on winter planning

Paper 6 – report from the Senedd's Citizen Engagement Team on the impact
of the waiting times backlog on people in Wales who are waiting for
diagnosis or treatment

8 Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment and Scrutiny of the Welsh Government's Health and Social Care Winter Plan 2021 to 2022: consideration of evidence

(14.45–15.00)

9 Legislative Consent Memorandum for the Nationality and Borders Bill: consideration of draft report

(15.00–15.15)

Paper 7 – draft report

Please note the draft report will be circulated as a supplementary pack.

[Written evidence](#)

10 Supplementary Legislative Consent Memoranda for the Health and Care Bill: consideration of draft report

(15.15–15.30)

(Pages 166 – 215)

Paper 8 – draft report

Paper 9 – Supplementary Legislative Consent Memorandum (Memorandum No 2) for the Health and Care Bill

Paper 10 – Supplementary Legislative Consent Memorandum (Memorandum No 3) for the Health and Care Bill

Paper 11 – legal advice note for the Supplementary Legislative Consent Memorandum (Memorandum No 2) for the Health and Care Bill

Paper 12 – legal advice note for the Supplementary Legislative Consent Memorandum (Memorandum No 3) for the Health and Care Bill

Document is Restricted

**Senedd Cymru's Health and Social Care Committee:
Inquiry into Hospital Discharge and its impact on patient flow through hospital**



Joint Written Response from the WLGA and ADSS Cymru

Background of the organisations

The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.

The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.

The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.

The Association of Directors of Social Services (ADSS) Cymru is the professional and strategic leadership organisation for social services in Wales and is composed of statutory directors of social services, the heads of service and tier three managers who support them in delivering statutory responsibilities: a group which consists of over 300 social services leaders across the 22 local authorities in Wales.

The role of ADSS Cymru is to represent the collective, authoritative voice of senior social care leaders who support vulnerable adults and children, their families, and communities, on a range of national and regional issues in relation to social care policy, practice, and resourcing. It is the only national body that articulates the view of those professionals who lead our social care services.

As a member-led organisation, ADSS Cymru is committed to using the wealth of its members' experience and expertise. We work in partnership with a wide range of partners and stakeholders to influence the important strategic decisions around the development of health, social care, and public service delivery. Ultimately our aim is to benefit the people our services support and the people who work within those services.

Introduction

Delays in hospital discharge and timely transfer of care to other secondary providers, primary care, and community care, have a significant impact on people in receipt of care their families and carers, as well as having an impact on those people requiring admission into hospital. Therefore, discharge and transfer of care planning and its effective implementation is everyone's business, with the Multi-Disciplinary Team (MDT) at both ends of the system being critical to its successful delivery.

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Delayed Transfers of Care (DToC) are seen as one of the main reporting mechanisms for the sector and are a benchmark used by Welsh Government to determine how well a health board and local authority are performing. The measurement of DToC has been described by the Wales Audit Office as the only national measure of discharge.¹ Over the past few years, there has been a great deal of work to both understand the issues and causes of DToC and poor patient flows, along with tools and resources to address these. A DToC is a symptom of a poorly aligned journey for people. Therefore, we must consider the wider challenges in the integration of health and social care support for our people. As such, a DToC cannot be considered in isolation. We must consider other factors and variables, including workforce supply indicators for the system.

The varying complexity of DToCs require effective partnership working by health and social care organisations, as well as third sector and commissioned providers. Moreover, in line with the Social Services and Well-being (Wales) Act 2014 and the Principles of Prudent Healthcare, joint working should be driven by the voice of individuals and carers and what matter to them, not just professionals. It is pivotal that the principles of co-production are at the centre of arranging and providing care because supporting people to safely transfer from one setting to the next, needs a person-centred, whole systems approach, with agreed joint protocols, effective communication, and flexible practices to achieve the best outcomes.

Therefore, a DToC can be an indication of both service pressures and ineffective collaboration, in terms of planning, commissioning and delivery, contributing to systemic failure, rather than the actions of individual parties, whether in social care or the NHS. Given that a DToC is such a complex issue, we strongly believe that in pursuing a whole systems approach in the planning, commissioning and delivery of health and care services, to fixate on this one area in isolation would be to miss the point. Fundamentally, we need to ensure we are shifting our focus from secondary hospital-based care to supporting independence, wellbeing and preventative care in the community, as articulated in *A Healthier Wales*. Historically, the majority of DToCs can be attributed to delays within the NHS itself. However, in the period just prior to the COVID-19 pandemic and despite much work being undertaken, there was evidence of an increase, in certain parts of Wales, in the proportion attributable to social care. This is an unfortunate reflection of the pressures faced by local councils, where the capacity of the workforce is a major contributory factor and so too, is the stability of the social care sector, particularly for domiciliary care and care homes.

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The COVID-19 pandemic has underlined the essential value of social care in helping people to live the lives they want to lead, demonstrating just how critical social care is. However, it has also brought into sharp focus the full range of challenges facing social care. Many of the pre-existing issues facing social care, including increasing demand, funding pressures and workforce challenges have been exacerbated and add to the significant pressures being experienced across the health and social care system, including in relation to DToC. We therefore welcome the Committee's inquiry looking at how flow through hospitals can be improved, but as cited earlier, feel this cannot be considered in isolation to factors across the whole system, including focussing on preventing hospital admissions. It will be important for the Committee to consider both the pre-existing challenges facing the system, as well as the significant immediate pressures being experienced as a direct result of the pandemic.

As part of the Committee's considerations, it will also be important to reflect on some of the work and research that has already been undertaken in this area over several years with the aim of improving flow. Some of the key areas of research are highlighted in Appendix 1, which should be supplemented with examples of best practice, as highlighted by Welsh Government in its May 2021 publication, *Delivering Home First*.ⁱⁱ

The Approach of Local Authorities

Councils across Wales have been doing all they can to reduce delays in getting patients out of hospital and back into the community, where the most efficacious level of rehabilitation and reablement can take place. However, social care is about far more than alleviating pressure on the health service; it is a vital and essential service in its own right, which provides care and support to maintain independence and improve well-being.

The focus of current policy is to shift demand from expensive services such as acute hospitals and nursing homes to managing conditions in a community setting. We believe that is the right approach and that policy aim must be continued, particularly considering the COVID-19 pandemic. There needs to be a shift in focus across the health and social care system as a whole, from health systems centred around hospitals, to health and social care systems focused on communities and community services as defined in their broadest sense. Making community-based and preventative care the central focus of the system requires a whole-systems approach to change, spanning hospital services, community services, primary care, and social care, as well as housing and other community resources.

The winter periods preceding the COVID pandemic, saw greater collaboration across services and organisations in support of improved flow of individuals using care and support through the hospital system and transferring to care in the community. For example, most

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local authorities have integrated nursing or intermediate care teams working in the community to 'pull' patients out of hospital back to their home or community, furnished with appropriate level of support they need to be re-abled and live as independently as possible. We believe the value demonstrated by these integrated teams who possess the skill, additional capacity, and critical local knowledge, lends itself to ensuring that the discharge policy function should primarily reside with the community and not with the hospital.

As collaborative partnerships continue to mature, so relationships between partners have continued to improve. Particularly as the work of the Regional Partnership Boards takes further root; partners now jointly own DToCs and collective action has been taken to try to tackle the issue.

Whilst progress continues across the regions in Wales, there have been a number of trends consistently reported by local authorities in relation to unscheduled pressures in previous years; many of which have been exacerbated by the demands placed on the health and social care system of trying to manage and suppress the pandemic. These include:

- **The fragility in domiciliary care and reablement services, exacerbated by market capacity, volatility in demand and short-term problems, associated with sickness or leave at times of public holiday.**
- **Responsiveness and complexity of service required are significant issues, with workforce recruitment and retention providing significant challenges.**
- **Capacity in traditional residential care had been relatively resilient, but many areas have reported a scarcity of specialist Elderly Mentally Infirm (EMI) and nursing care capacity (in part as a result of workforce issues and with a particular challenge with recruitment of nurses).**
- **Pressures on the hospital system, in particular increased admissions and people presenting with higher levels of acuity, coupled with the reduction of hospital beds.**
- **Patient/Family/Carer choice and expectations not being properly considered and managed.**

Impact of the Pandemic

While in recent months much of society had been looking towards the easing of restrictions and recovery, the health and social care sector has remained under considerable and increasing pressure. Social care has seen an unprecedented increase in demand for services. Some of this was latent demand while services were not operating at full capacity or specific

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services were not available (such as day centres) and some is new demand for care and support services, as a result of the indirect harm from delays in health care and treatment and family / carer breakdown. In addition, Long Covid has increased requests for support from social care services and the mental health and well-being impacts of the pandemic are well documented. There is a clear message being received from across the social care sector that they are still in response mode.

Both WLGA and ADSS Cymru continue to seek regular feedback from local authorities on the issues and concerns they are facing at the local level in delivering social care services. While the level to which specific issues are impacting locally can vary, all have highlighted concerns and challenges which reflect common pressures being experienced across both adult and children's services. These include:

Workforce - There are now significant challenges in relation to recruitment and retention both for in-house (including assessment and provision) and commissioned services across both adult and children's services. This issue has been exacerbated by number of issues including:

- Competition both from the health service and other sectors who can offer better terms and conditions. This has been further exacerbated because of a reduction in immigration since the UK left the EU, which has increased the need for the hospitality industry to recruit locally, effectively competing for the same pool of staff as social care.
- A reduction in staff prepared to continue to work in the sector, with some making lifestyle choices to reduce working hours and many leaving the sector because they are exhausted.
- Some have felt let down by the lack of recognition given to social care workers, with NHS workers seemingly more valued and so some are walking away.
- Increasing demand and pressure being placed on an under-valued and over-stretched workforce (with some employers unable to honour leave requests and employees exercising their zero hours contract rights).
- Difficulties in filling staff voids due to a large number of staff having to self-isolate.

Care at Home – Both in-house and commissioned services are under significant pressure, with demand for services increasing. Local authorities are experiencing domiciliary care packages being handed back which has a wider impact on reablement provision, hospital discharges, prevention of admissions and responding to urgent need.

Waiting lists – Waiting lists are increasing, people waiting for packages of care and for people awaiting assessment and/or equipment and support from occupational therapists.

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This also impacts on unpaid carers well-being as there are delays to provision of equipment and training/support to meet their cared for's needs

Unpaid Carers – There are increasing concerns for unpaid carers who have continued under severe pressure throughout the pandemic. While carer's services have continued to support people, there has been an increase in demand, with concerns that if unpaid carers are unable to continue to care effectively, then there will be increased demand for support placed on already overstretched services.

The unprecedented demand has led to several health boards, local authorities, and the Welsh Ambulance Trust to issue joint statements in recent weeks outlining the deeply concerning situation to the public. For example, the Cardiff and Vale region has seen a 30% increase in people needing care at home compared with pre-pandemic numbers. This huge increase in demand – alongside a UK-wide shortage of care workers and health care staff – is leading to delays in care provision and preventing the timely discharge of patients from hospital settings.

The statements have warned that across the health and social care system there is not the staff to cope with the sheer volume of people needing to be discharged from hospital with care packages or who need care in their own homes and communities. The significant delays in these services have led to a shortage of NHS beds, backlogs in areas like A&E, and the Welsh Ambulance Service looking after patients in their vehicles outside hospitals. As a result, partners have had to urge people to take on responsibility for looking after their loved ones – when they are medically fit to be discharged – to try and free up hospital beds. They have also called on people to return to the care sector if they have left or join a fast-track programme to become a qualified carer.

In responding to these challenges, councils and health boards are meeting regularly to review cases and address barriers on a person-centered level. Each council is aware of the cases within its own boundary and working with the health board to maintain an overview. A range of positive interventions have been put in place to improve flow through the system, both by councils, health boards and by working together. This includes new ways of working and further investment in capacity and continued efforts to recruit more staff. Further preventative work and focus to stop people entering hospital in the first place is also required.

It is also important to note that social care continues to support a significant number of people in the community, which prevent hospital admission in the first place. This far outweighs the number of delays in hospital discharges, which reflects that prevention and

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early intervention services play a critical role in reducing pressures in secondary care services.

As a result, there is a good knowledge and understanding of what is stopping medically fit people being discharged from hospital. There are a variety of reasons for the current delays in discharge, with the numbers and reasons for DToC changing on a day-to-day basis. Currently, there are two clear 'top' reasons as to why there are delayed transfers of care from hospital:

- Individuals are awaiting packages of domiciliary care (with a lack of capacity to provide new packages and also due to packages being handed back to councils); or
- Individuals are awaiting a place in residential care or nursing homes (including awaiting assessment by care home managers but also noting that COVID is still in circulation and impacting, for example patients waiting for COVID test results or care homes being classed as 'red').

In addition, there are a range of other issues which are having a significant impact, including:

- Awaiting social worker assessment.
- Awaiting reablement (including step down beds in some instances and therapy).
- Awaiting Occupational Therapist assessment.
- Awaiting NHS Continuing Healthcare or a number of health assessments (e.g., mental health or nursing assessments).
- Risk averse approach which over prescribes support arrangements and reduces supply of support services available and is based on deficit not peoples' assets.

Getting through the winter period is fast becoming the key priority for a number of councils, with the fragile situation in social care (Adults and Children's services) the key risk area. With the role social care plays in maintaining an appropriate flow through the health and social care system, along with other key partners such as housing, significant concerns remain about the ability of social care to maintain services to all those who currently receive care and support over the coming months, let alone meeting the continuing and ongoing increase in demand for services.

Discussions continue at the local, regional, and national levels to consider what support is available and what further actions can be taken to best support councils and health boards at the present time.

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The workforce is the most significant area of concern for councils at the moment. Workforce capacity and the significant challenges in recruitment and retention are issues that cut across all of the issues highlighted, and are the main reasons for the lack of capacity to provide packages of care needed to undertake assessments or provide reablement support; with the loss of existing staff and challenges in recruitment as significant concerns. While local authorities, private and third sector partners are all utilising the social care *WeCare.Wales* campaign and coordinating efforts to support improvements in awareness of the opportunities in social care, addressing the current pressures needs a multi-pronged approach.

We believe that there is a need for a clear and sustainable offer to stabilise the domiciliary care and care home workforce and to provide proper and fair remuneration for the workforce. Councils are fully supportive of the Welsh Government's intention to increase pay for social care workers to the Real Living Wage (RLW). However, it is becoming increasingly clear that our ambition must go beyond this if we really want to be able to offer 'fair pay' for those who are undertaking some of the most important roles in society. There is also a need to take immediate action – the workforce challenges are already with us, and so there is a need to do all we can to increase social care workers pay now, there is simply no room to delay.

Some proposed ways to support and grow the social care workforce put forward include:

- Incentives and Rewards for new and existing carers.
- Further extend *WeCare.Wales* publicity campaign to encourage new carers and the development and roll out of introduction to social care training programmes.
- Support Social Work and Occupational Therapist posts to improve recruitment and retention.
- The provision of ongoing support for existing workforce wellbeing.
- Increasing capacity in social work by removing administrative and liaison tasks.
- Increasing capacity in social work by employing managed agency staff.
- Ensuring that registration requirements of staff by Social Care Wales is proportionate and is sufficiently flexible to respond to changing contexts, i.e., flexibilities in workforce registration, including reducing barriers for new entrants.

Other steps that could be taken to support include:

- Work with UK bodies to reduce turnaround times for DBS applications - delays are preventing new staff taking up vacant posts in a timely way.
- Earlier referrals to social services for assessment, ideally when a patient enters the hospital system.

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- Consider the learning from the pilot in Gwent to support strengths-based approaches in hospital discharge supporting both the cultural and systems changes required to focus on what matters to individuals.
- Improved communication with the wards - often information is not passed between hospital staff and can result in mixed messages or conflicting information.
- Focus on better screening and decision making at the front doors of acute hospitals and within care homes, so that a positive risk approach is taken, to minimise the need for hospital admission, working to a 'home first' / D2RA model of community support, when planning for a discharge from hospital.

These steps are ones which can be taken in the short-term, but the current pressures have yet again laid bare the fragility of social care services and the need for long-term sustainable funding. This includes the need for continued investment in the immediacy to address unmet and under-met need, tackle rising pressures, retain hard working social care staff, and invest more in prevention. Local government has long been calling for a shift in focus across the health and social care system as a whole, from health systems centred around hospitals to ones where health and social care systems focus on place-based communities; primary and community services and wellbeing, addressing people's physical health, mental health and social needs together. Taking this approach and shifting resources into the community will support us in the longer term to take a far more preventative approach, focussing on preventing admissions to hospitals in the first place and preventing escalation of issues and the need for crisis responses. Such an approach will lead to better outcomes and experiences for families and less pressure on the health and social care system as a whole.

Key Actions

The previous section considered some of the immediate pressures and actions that need to be taken in order to manage the current unprecedented demand but looking to the longer term and given the profound impact that COVID has had, we need a longer-term vision which shapes a new patient pathway into and out of acute care. We believe that as part of the COVID recovery process, regional and national partners across health and social care need to reconsider the expanded research evidence that has been published over the past decade and in doing so, address the challenges set out within the seven key themes below:

PRE – ADMISSION

- **Prohibitive pathways** - we believe that the Wales Ambulance Service Trust must examine its pre-admission pathways to ensure that they are not prohibitive or focussed on presentation rather than on the individual.

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- **Personal choice and positive risk** – the person, their family, community networks etc. are all critical variables that must be considered from the beginning of the assessment process.
- **Options to refer to other agencies** – there are pockets of good practice across Wales with strong case examples to demonstrate this, but it needs to be spread wider.
- **Community alternatives for GP's** – General Practitioners are an essential core partner not just for the NHS as a provision of strategic advice but also in delivering community services, like operationally supporting reablement and other community-provided care. GP Cluster developments are enabling this consideration.

ADMISSION

- **Only admit if there is no other choice** – people are still admitted prematurely without other choices or options properly examined and risk assessed.
- **Focus must be on the person** – evidence suggests that people with co-morbidities will deteriorate in hospital, as will the strengths they have to draw on, both personally and from their families, communities, and other sources of support.
- **More resources to turn around and support in community** – not just services but also support for carers and investment in community infrastructure.

DISCHARGE

- **Develop a systems-wide approach to hospital discharge** - the inter-relationship between primary, secondary and community care needs to be understood and the discharge process looked at within the wider system and beyond this to families, carers, community support (addressing both formal and informal care networks).
- **Planning needs to start at point of admission** – it must be based on the person's choices and what is in their best interests from a holistic perspective, involving the individual, their families and carers and should be led by the Community Reablement Teams in the community.
- **Optimal discharge practice must be followed and adhered to** – Government guidance on discharging patients safely from hospital to other care settings has changed in light of the pandemic, with the requirement of a negative COVID test to negate virus transmission. To ensure there is safety parity in the system between health and social care services, good practice guidance must be properly followed by all partners to reduce the risk of community transmission.
- **Development of more appropriate step-down accommodation** – as more Discharge to Recover to Assess pathways are designated, then there is a need to identify and

resource more step-down bedded facilities, which could mean the restoration or re-purposing of NHS and council facilities.

COMPLEXITY

- ***There is a significant increase in complexity*** – those with complex needs are the ones that are stranded in the system and the longer they stay, the more moves between sites, the further complexity, leading to increases in DToC.
- ***Risk adversity increases with complexity in secondary care and leads to an over-prescription of care*** – this is dis-empowering and leads to deterioration, dependence and increases delays.
- ***Communities manage huge complexity*** – but need resources to expand and family/carer support.
- ***The lack of community-based support leads to increased complexity*** – during the COVID pandemic in particular, people are increasingly resisting access to services to minimise face-to-face contact and reduce the risk of transmission but then they reach a point where they find it difficult to cope (and is equally applicable for carers/families).

CULTURE

- ***Need to move from an illness/deficit model to a strengths-based model - focused on the individual and what matters to them***
- ***Conversations need to happen from the outset*** – real co-produced health care involving the person, their families and carers based on 'What Matters' and 'Last 1000 Days'.
- ***Culture needs to revert back to that of 'person centred' care and away from commodity-based care*** – so more focus on what the support the person really needs rather than on patient flow and bed numbers.
- ***Give clinical staff on wards the autonomy to support their own patients*** – this should be done in an integrated way rather than managing beds and bed occupancy.
- ***Implement existing guidance*** – leaders within the system need to ensure the guidance that exists on minimising delayed discharge is fully implemented and that all staff in the process are properly trained.

COMMUNICATION

- **Ensure there is an effective flow of information** - this includes IT systems, accurate and timely data entry and sharing of information across sectors, organisations and agencies.
- **Robust communication to ensure that all involved are aware and informed of planning and progress** - again co-produced with the person, their families/carers.

WORKFORCE

- **There must be a fully integrated workforce based in the community.**
- **Social care workforce must be properly remunerated and valued as a worthwhile profession** – this includes parity of esteem with the health work force in terms and conditions, careers development and training.
- **National government and statutory agencies with the mandate for workforce development need to expedite progress** – there is a need to mobilise and invest in the ambition of the health and social care workforce strategy

Conclusions:

The pressures on acute hospitals come from many sources and are a symptom of wider issues in the local health and social care system, suggesting that a more sustainable response will be developed by looking at the whole system. Even before the COVID-19 pandemic, health and social care practitioners were finding that problems that were usually confined to the winter months were now increasingly being experienced at other times of the year as well. Yet dealing with an unprecedented public health emergency has placed a new set of pressures on the system which need to be managed. The need to invest more in preventative services to keep people health and safe in their communities is now paramount.

A significant amount of learning has been undertaken over the past 5 years and there are certainly lots of excellent examples of good practice to highlight, like:

- A single point of access.
- The establishment of Intermediate Care Teams (ensuring the provision of co-ordinated services across health and social care).
- The establishment of Rapid Response Teams.
- Social care and third sector staff working alongside health staff in hospital to prevent delayed discharges; and

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- Extending the range of rehabilitation/reablement services (including the use of intermediate care flats as part of a wider health, social care and community complex).

Yet, despite the examples of good practice, the real difficulties in addressing the challenges presented by unscheduled care is the capacity of the organisations and resources available. Given the ever-growing pressure on services and the impact of cuts seen in previous years, particularly to local authority budgets, this will continue to be an issue. Whilst we understand that using Regional Partnership Boards is one mechanism to try to address this, enabling more joint decision-making across health and social care, there is also the need to fully acknowledge the significant pressures being faced by local authorities and ensure they are funded appropriately to meet these pressures; this is no more acutely felt than in the time of a national crisis.

People want to live in their own homes for as long as they can, including people with complex health and social care needsⁱⁱⁱ. Improved health care and a policy focus on choice and control means that both children and adults can expect to live in their own homes, with more complex health needs and enjoy longer lives. However, this in turn leads to a greater demand for care and support at home, as well as changing people's expectations regarding the management of need complexity if an acute episode of ill health emerges. People only ever want to go into hospital if there is no other choice and when they do, they want to be assured that they are there for a minimal amount of time and that there is a clear plan to return them to their residence of choice as quickly as possible, so they can be supported to continue to live their lives.

We believe the best way of achieving optimal person-centred choice and improved health and well-being outcomes is to ensure there is increased investment in early intervention and preventative services in the community, which will minimise acute health episodes and reduce the need for unscheduled admission for treatment and care. However, when unscheduled admission is required, then a clear plan to discharge which is person-centred and holistic is vital.

REFERENCES

ⁱ [Wales Audit Office, What's the hold up? Discharging Patients in Wales, 2019.](#)

ⁱⁱ [Welsh Government, Delivering Home First – Hospital to Home Community of Practice: key learning and practice examples, May 2021.](#)

ⁱⁱⁱ [Care and support at home in Wales Five-year strategic plan 2017-2022.](#)

APPENDIX 1:

Previous Research

In 2013, the Community Hospital Interface Group published its report on DToC and stated that if improving flow is to be assured on a sustainable basis, a three-stranded approach is needed:

- 1. A preventative approach which identifies those at risk of being admitted to hospital and seeks to intervene to avoid this where it is appropriate to do so.**
- 2. A proactive approach which identifies and manages those at risk of becoming delayed when in hospital.**
- 3. Effective systems and processes to identify and manage those who experience a delay in their discharge or transfer to a more appropriate setting.**

Following on from that research, the Social Services Improvement Agency also published a report entitled, [*Delayed Transfers of Care: Informal Review to Identify Good Practice \(2016\)*](#), which focused on operational practice, systems and processes within local authority and health board partnerships under the four themes of – Capacity, Consistency, Communication and Culture.

The research found there has been a conscious move towards rebalancing provision towards primary and community-led healthcare services. The move towards a more community driven NHS response had led to significant investments in community services, including the establishment of Community Resource Teams (CRTs). Local authorities in partnership with Health Boards have developed the CRTs and have also provided a shared approach to reablement, in addition to the longer-term domiciliary care provision. This reinforces the need for all responses to take a whole systems approach.

Several actions have been identified to improve performance in relation to DToC, these included:

- Implementation of existing guidance - such as [*'Passing the Baton'*](#) and the Ten High Impact Changes for Complex Care.
- Avoiding unnecessary hospital admissions – working with GPs to identify key people at risk to target early intervention, use of specialist staff at the “front door”, providing support and advice to care homes, use of third sector organisations in the provision of preventative services and support.

-
- Choice – ensure implementation of existing guidance, ensure staff are “on message” i.e., hospital is not accommodation; the need for early discussions to plan discharge; and improving the utility of intermediate care beds, step down beds, interim placements etc.

Research undertaken by the Institute for Public Care (IPC) at Oxford-Brookes University has continued to build on this work both in Wales and across the UK. In its report, [Reducing delays in hospital transfers of care for older people: Key messages in planning and commissioning \(2018\)](#), the principle author, Prof John Bolton, sets out a number of key steps health and social care providers can take to reduce DToCs. These include:

- Less focus on assessment (for longer term care) at the point of discharge and more focus on support for recovery, recuperation and rehabilitation with assessments taking place after this help has been offered – ‘discharge to support recovery – then to assess.’
- Develop a set of specifically commissioned services to help people recover post hospital.
- Commissioners to understand the volumes of care that are likely to be required in the short-term - there is a regular flow of people through the out of hospital care system with most not requiring longer term support (the system should not get “clogged up”).
- Those not requiring care should be let through the system quickly – with providers empowered to make the decision to end care where that is appropriate.
- Therapists and others in the MDTs to write recovery plans for people at point of discharge (everyone should have a fully drafted discharge plan).
- A greater focus on how to assist people to manage their long-term condition(s).

In his follow-up discussion paper, [Commissioning Out of Hospital Care Service to Reduce Delays \(2020\)](#), Prof Bolton sets out for health and social care organisations, a rationale for developing integrated strategies that can guide effective performance management, commissioning and day-to-day service delivery. At its core is the underlying principle that by focusing on achieving the right outcomes for people, tangible improvements in the effective use of resources should be seen. The paper, offers the following:

1. Considerations for health and social care partnerships on the behaviours that underpin integrated strategic demand management thinking.
2. Considerations for data collection to better understand supply, demand, and outcome focused performance of current and future service models.

-
3. A 'model' for describing the service elements that make up intermediate care services.
 4. Considering what a 'good' intermediate care system should achieve.



Hospital discharge and its impact on patient flow through hospitals

The British Association of Social Workers is the professional membership organisation for social work. With a membership of over 22000 we are the independent voice of social work that champions social work and helps members to achieve the highest professional standards.

Our five-year Vision from 2020 - 2025 is that *“Social work will be a thriving, influential, respected profession, improving lives and upholding people’s rights across the UK.”*

Our organisation Mission clarifies what we do, why we do it and who for:

BASW acts...

- For social workers: Supporting, protecting, and inspiring social workers in all roles, and the next generations of professionals.
- For social work: Developing professional ethics, practice, knowledge, research, and learning.
- For a better society: Speaking out for social work and social workers on social justice, equality, poverty, human rights, oppression, and other vital social issues in the UK and internationally.

The scale of the current situation with delayed transfers of care from hospital?

The chart below represents a snapshot of the delays to transfer of care to both recovery pathways and those by-passing recovery pathways between 10/07/2020 and 30/11/2021. <https://statswales.gov.wales/catalogue/health-and-social-care/nhs-performance/delayed-transfers-of-care>

Table 1

Date	Type 1 People awaiting transfer from hospital to recovery pathways	Type 2 People awaiting transfer out of recovery pathways and on to longer-term care	Type 3 People awaiting transfer from hospital to longer-term care, bypassing recovery pathways	Total Delays
10/07/2020	327	289	26	642
30/11/2021	328	527	213	1,068

It's important to note that the numbers in each category have decreased and increased over the salient timeframe. In November 2021 the numbers awaiting transfer from hospital to recovery pathway remains almost the same. The numbers awaiting transfer out of recovery pathways and on to longer-term care, or awaiting transfer from hospital to longer-term care, bypassing recovery pathways have however, increased significantly. These delays to longer term care and will include people who have complex non-acute health conditions and sadly, those who should be on a palliative care pathway and who should be receiving end of life care.

Each delayed transfer represents a real person who is not receiving care and support in the right place and whose potential to benefit from a recovery pathway, to return home, or to settle into a long-term care placement becomes compromised in direct proportion to the amount of time they spend in an acute hospital setting. Antonio Rojas-Garcia et al research in 2018 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5750749/> suggests that the *'adverse effects of delayed discharge are both direct (through increased opportunities for patients to acquire avoidable ill health) and indirect, secondary to the pressures placed on staff.'* This is amplified for older people where every extra day in hospital adds risks of functional decline. We already know that large number of hospital patients developed hospital acquired Covid 19 infection, amounting to 1% of all Covid 19 infections and the Welsh Government has committed 4.5 million to investigate and learn from hospital acquired infection. <https://media.service.gov.wales/news/more-than-gbp-4-5m-to-investigate-and-learn-from-hospital-acquired-covid-19-infections-in-wales> We are also all too aware of the pressure that has been placed upon on front-line NHS staff throughout the pandemic.

A hospital is not the right environment for people to make long-term decisions about their ongoing care and support needs, assessments should be at home with families, carers or advocates, after reablement or rehabilitation if required.

Our members are reporting delayed transfers of care at a scale not experienced by them previously, which is supported by the data in Table 1.

The impact of delays in hospital discharge, both on the individual and the patient flow through hospitals and service pressures?

One of our members recently told us that the current situation is the worse it's been in 30 years of them being a social worker. When assessments are undertaken there is a lack of care home places or no availability of domiciliary care. One member remarked that domiciliary care agencies are handing back referrals as they have no staffing capacity to meet the demand. These factors increase the risk of institutionalisation, loss of confidence and motivation to move on, which in turn, increases the pressure on unpaid carers to step in.

Delayed transfer from a care setting to home, once assessment has been completed, means less care home places available for transfer to assess, or for long term care, from a hospital setting.

Our members have told us that there have been times when social workers have not been able to access wards during the pandemic due to not being 'clinical' staff. Particularly during lockdowns, our members have felt that their essential role in supporting ethical transition from a hospital to a more appropriate setting, was not always fully integrated into cross-infection guidance. Social workers are an essential element of the multi-disciplinary workforce.

Sickness amongst social workers in some hospital social work teams has impacted clearly on the timeliness of assessments being undertaken.

The impact of home working on being able to undertake assessments consistently and robustly has been a source of concern for some of our members. Some of this relates to the availability of devices for patients, the availability up of nursing staff and support staff to support these remote assessments and the lack of private spaces for patients to talk about confidential and family matters. Undertaking remote assessments is challenging at the best of times and this is amplified when a patient being assessed has cognitive or sensory impairment, especially when family or advocates have been unable to support the process due to Covid restrictions. Social workers are concerned that the rights of such patients are being compromised, because their ability to fully participate is not always able to be realised, despite the best intentions of social workers and health staff trying to support the process. People need choice and control so support is built around their strengths, own networks of support, and resources (assets) that can be mobilised from the local community.

The variations in hospital discharge practices throughout Wales and cross-border, and how they are meeting the care and support needs of individuals?

A consistent approach which is co-produced, and rights based, is essential. Our members feel, that at times, these approaches and values have been a casualty of the pandemic, with patient choice being a primary concern.

Approached like 'Discharge to Assess' can build more consistency and reduces local variation but will not achieve its fundamental aim until capacity and workforce issues are addressed.

The support, help and advice that is in place for family and unpaid carers during the process?

Our members have experienced an increased pressure on unpaid carers to accept the care of family members. This can result in carer burnout and breakdown of the caring arrangement risking the cared for person potentially returning to hospital, as no other alternatives available. It could also potentially result in lead to safeguarding concerns through carer stress. We know that through Carers Wales *Track the Act* <http://www.lukeclements.co.uk/track-the-act/> that the implementation of the Social Services and Wellbeing (Wales) Act 2014 has not improved the life of unpaid carers in Wales and not led to an increase in carers assessments, this was pre-covid, the situation for unpaid carers has not improved during the pandemic. Attention must be paid to the ongoing needs and support offered to unpaid carers to ensure viability and sustainability.

What is needed to enable people to return home at the right time, with the right care and support in place, including access to Reablement services and consideration of housing needs?

The recruitment and retention crisis in the social work and the social care workforce must be addressed along with ongoing support for the wellbeing of a workforce which is under unprecedented stress and pressure.

Unhelpful distinctions between clinical and non-clinical staff need to be removed if patients are to benefit from an integrated health and social care workforce, working jointly to support timely and ethical transfer from hospital.

Family and/or professional advocates need to be accepted as a vital part of the multi-disciplinary team and their essential role in supporting patient voice and choice understood.

Where patients live outside of bricks and mortar housing, for example Gypsies and Travellers living in trailers, more creative and flexible approaches to adapting trailers for those wanting to return to their homes, living in a way which is consistent with identity and ethnicity. The danger is that Gypsies and Travellers may be forced into bricks and mortar accommodation with devastating consequences for their identity and mental health.

Care home providers concerns about viability and rising costs must be addressed, as do concerns about contractual obligations for staffing levels and activities, contingency planning and how to share risk with commissioners.

Allison Hulmes

National Director for Wales

BASW Cymru



HSC(6)-10-22 Papur 3 / Paper 3

RESPONSE TO THE SENEDD HEALTH & SOCIAL CARE COMMITTEE CONSULTATION ON HOSPITAL DISCHARGE AND ITS IMPACT ON PATIENT FLOW THROUGH HOSPITALS

Who are we?

Care Forum Wales is the leading professional association for independent sector social care providers in Wales with over 450 members. Our membership includes those who provide care homes and domiciliary care services. Our members come from both the private and third sectors and we aim to engage and professionally support independent providers, to spread good practice, and help members provide a high quality service.

Our members include a variety of structures: large corporate groups, home-grown small and medium enterprises (SMEs), registered social landlords, and voluntary and charitable organisations.

Background

As the First Minister himself said the sector was fragile going into the pandemic. The majority of social care in Wales is commissioned by the public sector (local authorities and health boards), rather than by private payers, and fees have been set based on the assumption that workers in the sector will be paid at or just above the legal minimum wage. There have been long been difficulties in recruiting and retaining staff and these have been exacerbated by the pandemic.

Current position

At the time of writing in early January with high omicron rates in the community both the NHS and the social care sector are under immense staffing pressure with increasing numbers of staff isolating after having tested positive for covid variant or waiting for PCR test results to return to work after being in contact with someone with covid. The pressures the sector is under have also limited our capacity to gather information from providers to contribute to this response. However, both homecare providers and care homes report being unable to take on care of new people due to staffing pressures. While this has been the case for some time in domiciliary care it is only relatively recently, during the pandemic, that it has become a significant issue in care homes too.

However, there are other structural issues too. Care homes are registered with Care Inspectorate Wales and have a Statement of Purpose detailing what types of care they can provide and are required to only admit residents whose needs they are satisfied they can meet. This is often poorly understood by colleagues in the Health Service who think that if a



bed in a care home is available then the care home should just admit the person who is the highest priority for discharge and if the care home is not prepared to do that they are simply being difficult.

What needs to improve

As previously detailed there can be tensions between care homes and hospitals about discharge policies. What is needed is an ongoing and trusted working relationship. People's needs are not necessarily easily pigeon hole and there will be many borderline cases where care homes are uncertain whether they could meet an individual's needs. They are more likely to have confidence they can do so after performing an individual assessment, when they have a relationship with and confidence that the member of hospital staff who is providing them with information is doing so fairly and when they know that appropriate primary and community support is available if they need it. The worst example we have heard recently from a member is where they were told a potential resident with dementia would need to be nursed in bed: when the care home manager went to the hospital to assess her needs she was standing at the nurses station shouting! Both sets of needs can be met but a care home needs to understand accurately what an individual's needs are before committing to meet them. Care homes will also need to balance the needs within the home: it may be that they can take a certain number of people with very high needs, but not more than that while providing safe care. Finances will come into this too of course: some potential residents may need additional staff support and this will need paying for. The smoother the process the better for everyone. We sadly often hear of potential admissions to care homes being delayed, perhaps while funding is confirmed and the person involved becoming ill again or passing away while waiting to move.

The most important thing is an ongoing, partnership based and mutually respectful relationship between Health Boards and care homes. Issues can be overcome together.

*Mary Wimbury
Chief Executive
7 January 2022*

I can confirm that we understand our evidence may be published.

Russell George MS
Chair
Health and Social Care Committee

SeneddHealth@senedd.wales

2 February 2022

Dear Russell

Thank you for the Health and Social Care Committee's report on the Legislative Consent Memorandum (LCM) on the Health and Care Bill, laid 16 December 2021.

The position has been superseded by a number of amendments made to the Bill and two Supplementary LCMs laid on 17 December 2021 and 28 January 2022 respectively. This letter therefore reflects the latest position on the Bill in responding to the Committee's recommendations.

Firstly, I welcome the Committee's confirmation that it has no objection to the Senedd giving its consent to the inclusion in the Bill of:

- Clause 77 (formerly Clause 75) (Tidying up etc provisions about accounts of certain NHS bodies);
- Clause 80 (formerly Clause 78) (Hospital patients with care and support needs: repeals etc);
- Clause 87 (formerly Clause 85) (Medicines information systems) as amended by the House of Commons on 23 November 2021;
- Clause 142 (formerly clause 123) (regulation of health care and associated professions) as amended by the House of Commons on 23 November 2021; and
- Clause 146 (formerly Clause 127) (Food information for consumers - power to amend retained EU law).

I note the Committee's views regarding clauses 88-94 (formerly clauses 86-92): Arm's Length Bodies Transfer of Functions and I consider the amendments tabled by the UK Government on 24 January 2022 will, if passed, address the Committee's concerns regarding these clauses. The detail of the amendments is set out in the Supplementary Legislative Consent Memorandum (Memorandum No 3) laid on 28 January 2022.

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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.

Please find my responses to your specific recommendations below.

Recommendations 1 and 2 - Clause 136 (formerly Clause 120): International Healthcare Arrangements

Recommendation 1

The Minister for Health and Social Services should make representations to the UK Government for an amendment to be brought forward to include on the face of the Bill a clear and proportionate test for what would qualify as an 'exceptional circumstance' for the purposes of the amount or type of healthcare that can be funded outside of an international healthcare agreement.

Response

Section 1 of the Healthcare (European Economic Area and Switzerland) Act 2019 (HEEASAA) currently provides the Secretary of State with a power to make payments, and arrange for payments to be made, in respect of the cost of healthcare provided in an EEA State or Switzerland.

Clause 136 (formerly clause 120) of the Bill will remove the power in section 1 of HEEASAA and replace it with regulation making powers enabling the Secretary of State to make regulations (a) for the purpose of giving effect to a healthcare agreement (including about making payments) between the UK and either a country or territory outside the UK or an international organisation, and (b) authorising the Secretary of State to make a payment in respect of healthcare provided otherwise than under a healthcare agreement, in a country or territory with which the UK has a reciprocal healthcare agreement, but only where the Secretary of State considers that the payment is justified by exceptional circumstances.

The purpose of the power enabling the Secretary of State to fund healthcare outside of an international healthcare agreement in exceptional circumstances is to assist the UK Government in supporting the healthcare needs of British residents when they are abroad in circumstances which might otherwise narrowly fall outside of a reciprocal healthcare agreement.

The UK Government has previously, for example, used existing powers under HEEASAA to provide crisis mental healthcare support to a minor in the EU where the Member State stated that the treatment was not covered under the European Health Insurance Card (EHIC) scheme. The UK Government has also funded treatment in the EU for twins with infantile haemangiomas who were born to UK residents but were unable to easily travel back to the UK due to COVID-19 travel restrictions and the risks of travelling at the time. They would not otherwise have been in scope of the planned treatment provisions in the EU reciprocal healthcare agreements as they could have received the treatment in the UK without undue delay had they been in the UK at the time.

Payments for healthcare outside the UK is a reserved matter because it concerns the welfare of people outside of the UK, and has no material bearing on, or connection to the domestic provision of healthcare in the UK; it is a matter of international relations whether and to what extent the UK decides to arrange and fund healthcare for people outside the UK.

Exceptional circumstances are likely to be those in which the refusal to fund healthcare treatment would result in unjustifiably harsh consequences for the individual such that the refusal of an application for funding would not be proportionate. Determining whether a payment is justified by exceptional circumstances will necessarily require a balance to be

struck between any competing public and individual interests involved. Attempting to define this further in primary legislation by reference to an amount or type of healthcare that can be funded would unduly restrict the Secretary of State's ability to exercise this discretion and hinder the ability to assist British residents when they most need it.

It is therefore my view that it is not appropriate to put a clear and proportionate test on the face of the Bill for what would qualify as an 'exceptional circumstance' for the purposes of the amount or type of healthcare that can be funded outside of an international healthcare agreement, as this could have a detrimental or limiting impact to provide support when needed.

Recommendation 2

Before the Senedd is asked to decide whether or not to give its consent to the inclusion in the Bill of clause 120 (now clause 136) (international healthcare agreements), the Minister for Health and Social Services should ensure that all Members have been provided with a copy of the final Memorandum of Understanding agreed between the UK Government and the Welsh Government in relation to the Healthcare (European Economic Area and Switzerland Arrangements) Act 2019.

Response

I am pleased to enclose the reciprocal healthcare Memorandum of Understanding (MOU) with this letter for the consideration of the Committee, which has been revised in the light of the Bill provisions. The MOU has been agreed by all four nations. The Committee will wish to note that the wider linkages in relation to the new intergovernmental relations (IGR) governance arrangements have not yet been included in the MOU but are being considered. The MOU will be updated to reflect the new IGR arrangements in due course.

Recommendation 3 - Clause 142 (formerly Clause 123): Regulation of Healthcare and Associated Professions

Recommendation 3

The Minister for Health and Social Services should outline what analysis has been undertaken by the Welsh Government of the risks and benefits associated with regulating, or not regulating, senior health leaders and managers in Wales, and what the rationale is for her decision not to introduce such regulation.

Response

Clause 142 (formerly clause 123) has been amended to provide that no recommendation is to be made to Her Majesty to make an Order in Council under section 60 of the Health Act 1999 which relates to any group of workers, who are not professionals but who are concerned with the physical or mental health of individuals, where the Order contains provision that is within the legislative competence of the Senedd, unless the Welsh Ministers have consented to that provision.

No decision with regard to the regulation of these workers (which includes senior health leaders and managers in Wales) by Order in Council has yet been taken. Should the UK Government decide to regulate with regard to such professionals at a future point, if this was to also apply in Wales, then the Welsh Ministers will consider whether or not to consent to an Order making such provision. Such a decision would be supported by relevant evidence as to the risks, costs and benefits of applying the regulations within Wales.

We have no plans to regulate senior health leaders and managers in Wales and the configuration of the NHS within Wales make this an unlikely event in the future. The Department of Health and Social Care has also indicated that it has no specific plans to regulate this group of workers in the near future.

I am content this amendment addresses our concerns in respect of this provision and consequently I can now support this Bill clause.

Recommendation 4 - Clauses 149, 144 and 91 (formerly clauses 89, 125 and 130): Consequential Amendments to Senedd Legislation

Recommendation 4

Before the Senedd is asked whether to give its consent to the Bill, the Minister for Health and Social Services should provide a further update on her discussions with the UK Government on the consequential amendment powers in clauses 89, 125 and 130 of the Bill (as introduced), including whether, in her view, the assurances she has received from the UK Government in respect of the proposed use of the powers reduce the associated risks to acceptable levels.

Response

These clauses provide the Secretary of State with the powers, by regulation, to make provision which is consequential on the Bill. This includes provision that amends, repeals, revokes or otherwise modifies provision made by, or under, an Act or Measure of the Senedd.

As set out in the Supplementary LCM (Memorandum No. 3) laid on 28 January 2022, I and my officials have met with the Minister of State for Health, Edward Argar MP and his officials on a number of occasions to discuss these provisions. The UK Government is of the view that these are standard clauses and it is the case that Wales similarly takes powers in Senedd Acts to make consequential amendments to UK Government legislation.

UK Government officials have provided examples of how these powers may be used – the amendments likely would be of a minor nature, for example the changing of the name of an English organisation which is referred to in Senedd legislation where a transfer of functions has occurred. The Minister of State for Health has also given a written commitment to making a Dispatch Box Statement in relation to clauses 91 and 149, on how these powers might be used.

Clause 144 refers to Schedule 17 which amends the Communications Act 2003 to restrict the advertising of certain food and drink products in relation to the UK. The Clause and Schedule are covered in the first LCM on the Bill. Whilst this clause also contains provisions which enable consequential change to Senedd legislation, the UK Government has not identified this as a clause which requires the legislative consent of the Senedd and therefore will not include within the wording Dispatch Box Statement. However, on the basis of the assurances provided by the UK Government on the possible use of the powers, I accept the consequential amendments which might arise from clause 144 as an acceptable and minor constitutional risk.

We have agreed the wording of the Dispatch Box Statement with UK Government and the UK Government has committed to making the statement prior to the Legislative Consent Motion debate in the Senedd scheduled to take place on 15 February.

On the basis of the statement being made, and in the light of all of the assurances given by the UK Government, I regard the risk presented by the provisions now to be acceptable.

Recommendations 5 and 6 – Laying of LCMs and Content of LCMs

Recommendation 5

The Welsh Government should ensure that LCMs are normally laid no more than two weeks after a Bill is introduced in accordance with Standing Order 29.2(i). Should circumstances require a delay before an LCM is laid, the relevant Minister should write to the appropriate Senedd committees to provide an estimate of when the LCM will be brought forward.

Response

The Standing Order deadline is potentially achievable for Bills on which the Welsh Government and the UK Government have worked closely together and are in agreement. The “normally” qualification recognises the realities of what is a highly variable process. The increasing size and complexity of Bills and whether the UK Government has shared draft provisions, which is at its discretion, in advance of publication, can impact our timing for laying LCMs.

We will consider the amendment of the formal guidance for completing LCMs as part of our engagement with the Business Committee’s review of the LCM process to make writing to the Senedd Committees as described a requirement. In the meantime, when laying LCMs in more recent times, we have included explanation regarding any delay in laying within the LCM itself, to ensure Members are informed.

In addition where possible we have laid LCMs within the two week deadline to ensure the Senedd Committees have as much time as possible to scrutinise the LCM. For example I laid Supplementary LCM, Memorandum No. 3 on this Bill on 28 January, just four days after the tabling of UK Government amendments to the Bill.

Recommendation 6

The Welsh Government should ensure that the LCMs it lays provide the relevant committees with sufficient information about the Welsh Government’s position, its concerns, any remedies it is seeking, and such other matters as may be appropriate to enable full and effective scrutiny.

Response

When preparing LCMs, the Welsh Government seeks to fully inform Members of the extent of its position with regard to clauses engaging the LCM process, and of the position with regard to negotiations with the UK Government. However, as you will appreciate, there is a need to respect confidentiality, and we may not always be in a position to share all the information we receive. The negotiations with regard to this Bill have been successfully completed and the outcomes are set out in the Supplementary LCMs (Memorandum No 2 and Memorandum No 3) laid on the Bill.

I trust this response will be helpful in the Committee’s scrutiny of the Legislative Consent Memoranda on the Bill.

I am copying this letter to Huw Irranca-Davies MS, Chair of the Legislation, Justice and Constitution Committee.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

Eluned Morgan AS/MS

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



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

2 February 2022

Dear Huw

Thank you for the Legislation, Justice and Constitution Committee's report laid on 3 December on the Legislative Consent Memorandum (LCM) for the Health and Care Bill (the Bill).

I note the Committee's comments on the first LCM laid on 1 September.

The position has been superseded by a number of amendments made to the Bill and two Supplementary LCMs laid on 17 December 2021 and 28 January 2022 respectively. This letter therefore reflects the latest position on the Bill in responding to the Committee's recommendations.

Please find my responses to your specific recommendations below

Recommendation 1 - Clause 87 (formerly Clause 85) (Medicines information systems)

Recommendation 1

The Minister should, in advance of the Senedd's debate on the relevant consent motion, provide further details of the intergovernmental discussions regarding clause 85 and confirm whether the amendments she has sought will be tabled to the Bill by the UK Government

Response

As set out in the Supplementary LCM (Memorandum No. 2) laid on 17 December, the UK Government has amended the Bill to address our concerns regarding clause 87 (formerly clause 85).

In relation to inappropriate use of data, the scope of the purposes for which medicine information systems regulations can be made under clause 87 is now limited. The clause now provides that provision in the regulations for a purpose in relation to clinical decision

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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.

making can only be made where there is a connection with the safety of such decisions relating to human medicines.

Our concerns regarding the availability of data to the Welsh Ministers for purposes within devolved competence such as clinical decision making, and further concerns regarding the overlap of data collection for the purposes of the Registry with existing data gathering in Wales have also been addressed, as well as the commitment to consult on provisions made in regulations made under the provisions. The clause now provides that that secondary legislation made under it must provide for information to be collected by the Welsh Ministers or a person designated by them such as Digital Health and Care Wales (DHCW), subject to specified exceptions in that secondary legislation. The amendment ensures where appropriate, data remains available for use by the Welsh Ministers.

Finally, in addition to the safeguards agreed on the face of the Bill as introduced, there is now a requirement that the Welsh Ministers be consulted on any regulations or directions relating to medicine information systems which relate to Wales. This will be supported by a Memorandum of Understanding to be developed and agreed between the UK Government and the Devolved Governments. We have communicated to UK Government the need to develop this Memorandum as soon as possible with a view to it being in place before the provisions come into force.

Taken together I am content that the amendments made to these provisions address our key concerns and consequently I can now support this Bill clause.

Recommendations 2 and 3 - Clauses 88-94 (formerly Clauses 86-92): Arm's Length Bodies Transfer of Functions

Recommendation 2

The Minister should, in advance of the Senedd's debate on the relevant consent motion, provide further details of the intergovernmental discussions regarding clauses 86 to 92 and confirm whether the amendments she has sought will be tabled to the Bill by the UK Government.

Response

My two major concerns in this area have been addressed.

On 24 January 2022, the UK Government tabled an amendment providing for a statutory consent requirement, whereby the consent of the Welsh Ministers is required before the Secretary of State can make regulations under clauses 89 (formerly clause 87) (Power to transfer functions between bodies) or clause 90 (formerly clause 88) (Power to provide for exercise of functions of Secretary of State) where those regulations contain provision which would be within the legislative competence of the Senedd if contained in an Act of Senedd Cymru (and is not merely incidental to, or consequential on, provision which would be outside that legislative competence) or which modifies the functions of the Welsh Ministers (i.e. modifies their executive competence).

Further detail regarding this amendment is set out in the Supplementary LCM (Memorandum No. 3) laid before the Senedd on 28 January 2022.

With regard to my concern about the ability of the Secretary of State to transfer property, rights and other liabilities from Arm's Length Bodies to the Welsh Ministers, Welsh NHS Trusts and Wales-only Special Health Authorities in clause 92 (formerly clause 90), to resolve this, the UK Government also tabled, on 24 January, amendments removing the

Welsh Ministers, Welsh NHS Trusts and Wales-only Special Health Authorities from the list of “appropriate persons” in the clause, thus fully addressing our concerns in this area.

In my view, my concern regarding clause 91, which provides the Secretary of State with the power to, by regulations, make provision which is consequential on clauses 88 or 90 (formerly clauses 86 and 88) of the Bill, has been addressed by the UK Government as set out in the response to Recommendation 8, below.

Recommendation 3

The Minister should seek an amendment to the Bill to address her concerns regarding clause 87 to the effect that the Secretary of State cannot use the powers therein to transfer and/or delegate functions in relation to Special Health Authorities, where those functions were directed by the Welsh Ministers in relation to Wales.

Response

As set out in my response to Recommendation 2, above, subject to the passing of the UK Government amendments laid on 24 January, this power can only be exercised with the consent of the Welsh Ministers, thus fully addressing our concerns in this area.

Recommendations 4 and 5 - Clause 136 (formerly Clause 120): International Healthcare Arrangements

Recommendation 4

The Minister should, in advance of the Senedd’s debate on the relevant consent motion, provide the Committee and all Senedd Members with a copy of the final Memorandum of Understanding (MoU) in place between the Welsh and UK Government’s in relation to the Healthcare (European Economic Area and Switzerland Arrangements) Act 2019, and confirm that the text of the MoU reflects the final, limited scope of the Bill as agreed by the UK Parliament

Response

I am pleased to enclose the reciprocal healthcare Memorandum of Understanding (MOU) with this letter for the consideration of the Committee, which I can confirm reflects the Bill provisions as amended on 23 November 2021. The MOU has been agreed by all four nations. The Committee will wish to note that the wider linkages in relation to the new intergovernmental relations (IGR) governance arrangements have not yet been included in the MOU but are being considered. The MOU will be updated to reflect the new IGR arrangements in due course.

Recommendation 5

The Minister should seek an amendment to the Bill to the effect that a clear and proportionate test for what qualifies as an ‘exceptional circumstance’ in clause 120 is included on the face of the Bill.

Response

Section 1 of the Healthcare (European Economic Area and Switzerland) Act 2019 (HEEASAA) currently provides the Secretary of State with a power to make payments, and arrange for payments to be made, in respect of the cost of healthcare provided in an EEA State or Switzerland.

Clause 136 (formerly clause 120) of the Bill will remove the power in section 1 of HEEASAA and replace it with regulation making powers enabling the Secretary of State to make regulations (a) for the purpose of giving effect to a healthcare agreement

(including about making payments) between the UK and either a country or territory outside the UK or an international organisation, and (b) authorising the Secretary of State to make a payment in respect of healthcare provided otherwise than under a healthcare agreement, in a country or territory with which the UK has a reciprocal healthcare agreement, but only where the Secretary of State considers that the payment is justified by exceptional circumstances.

The purpose of the power enabling the Secretary of State to fund healthcare outside of an international healthcare agreement in exceptional circumstances is to assist the UK Government in supporting the healthcare needs of British residents when they are abroad in circumstances which might otherwise narrowly fall outside of a reciprocal healthcare agreement.

The UK Government has previously, for example, used existing powers under HEESAA to provide crisis mental healthcare support to a minor in the EU where the Member State stated that the treatment was not covered under the European Health Insurance Card Scheme. The UK Government has also funded treatment in the EU for twins with infantile haemangiomas who were born to UK residents but were unable to easily travel back to the UK due to COVID-19 travel restrictions and the risks of travelling at the time. They would not otherwise have been in scope of the planned treatment provisions in the EU reciprocal healthcare agreements as they could have received the treatment in the UK without undue delay had they been in the UK at the time.

Payments for healthcare outside the UK is a reserved matter because it concerns the welfare of people outside of the UK, and has no material bearing on, or connection to the domestic provision of healthcare in the UK; it is a matter of international relations whether and to what extent the UK decides to arrange and fund healthcare for people outside the UK.

Exceptional circumstances are likely to be those in which the refusal to fund healthcare treatment would result in unjustifiably harsh consequences for the individual such that the refusal of an application for funding would not be proportionate. Determining whether a payment is justified by exceptional circumstances will necessarily require a balance to be struck between any competing public and individual interests involved. Attempting to define this further in primary legislation by reference to an amount or type of healthcare that can be funded would unduly restrict the Secretary of State's ability to exercise this discretion and hinder the ability to assist British residents when they most need it.

It is therefore my view that it is not appropriate to put a clear and proportionate test on the face of the Bill for what would qualify as an 'exceptional circumstance' for the purposes of the amount or type of healthcare that can be funded outside of an international healthcare agreement as this could have a detrimental or limiting impact to provide support when needed.

Recommendation 6 - Clause 142 (formerly Clause 123): Regulation of Healthcare and Associated Professions

Recommendation 6

The Minister should, in advance of the Senedd's debate on the relevant consent motion, provide further details of the intergovernmental discussions regarding clause 123 and confirm whether the amendment she has sought will be tabled to the Bill by the UK Government.

Response

I can confirm that the amendment we sought was achieved and the Bill amended so as to require the consent of the Welsh Ministers to an Order in Council made under section 60 of the Health Act 1999, which makes provision that is within the legislative competence of the Senedd and brings into regulation a group of workers who are not professionals, but who are concerned with the physical or mental health of individuals.

Further detail of the amendment is set out in the Supplementary LCM laid before the Senedd on 17 December 2021.

Recommendation 7 - Clause 144 and Schedule 17 (formerly Clause 125 and Schedule 16): Advertising of Less Healthy Food and Drink

Recommendation 7

The Minister should, in advance of the Senedd's debate on the relevant consent motion, provide further details of the intergovernmental discussions regarding clause 125 of and Schedule 16 to the Bill.

Response

I set out in my letter of 28 October 2021 to the Committee that whilst the substantive content of the clauses covering restrictions on the advertising of unhealthy food on a four nations basis is welcomed, there is consequential power included enabling the Secretary of State to amend Welsh legislation.

It should be noted that this is an area of the Bill which the UK Government does not accept is devolved and therefore does not agree should be subject to a requirement for the legislative consent of the Senedd.

However, as set out in the response to Recommendation 8, below, on the basis of the assurances provided by the UK Government on the possible use of the powers, we accept the consequential amendments which might arise from clause 144 (formerly clause 125) as an acceptable and minor constitutional risk.

Recommendation 8 - Clauses 149, 144 and 91 (formerly clauses 89, 125 and 130): Consequential Amendments to Senedd Legislation

Recommendation 8

The Minister should seek an amendment to the Bill to the effect that the powers in the Bill cannot be used by UK Ministers to make regulations that amend the Government of Wales Act 2006.

Response

These clauses provide the Secretary of State with the power, by regulations, to make provision which is consequential on the Bill. This includes provision that amends, repeals, revokes or otherwise modifies provision made by, or under, an Act or Measure of the Senedd.

As set out in the Supplementary Legislative Consent Memorandum (Memorandum No. 3) laid on 28 January 2022, I and my officials have met with the Minister of State for Health, Edward Argar MP and his officials on a number of occasions to discuss these provisions. The UK Government is of the view that these are standard clauses and it is the case that Wales similarly takes powers in Senedd Acts to make consequential amendments to UK Government legislation.

UK Government officials have provided examples of how these powers may be used – the amendments likely would be of a minor nature, for example the changing of the name of an English organisation which is referred to in Senedd legislation where a transfer of functions has occurred. The Minister of State for Health has also given a written commitment to making a Dispatch Box Statement in relation to clauses 91 and 149, on how these powers might be used. (As advised in response to Recommendation 7 above, the UK Government has not identified clause 144 as requiring the legislative consent of the Senedd and therefore will not include in the Dispatch Box Statement).

We have agreed the wording of the Dispatch Box Statement with UK Government and the UK Government has committed to making the statement prior to the Legislative Consent Motion debate in the Senedd scheduled to take place on 15 February.

On the basis of the statement being made, and in the light of all the assurances given by the UK Government, I regard the risk presented by the provisions now to be acceptable.

I trust this response will be helpful in the Committee's scrutiny of the Legislative Consent Memoranda on the Bill.

I am copying this letter to Russell George MS, Chair of the Health and Social Care Committee.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

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**

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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

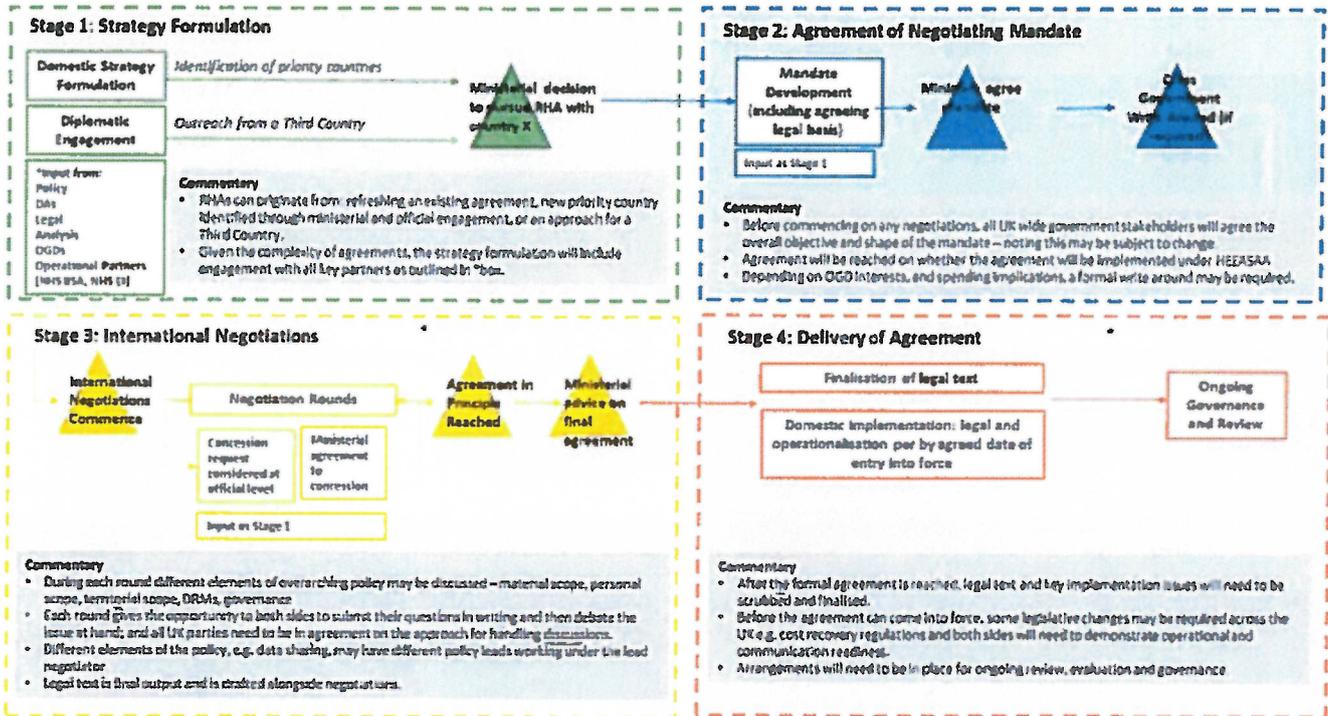
Cabinet Secretary for Health and Social Care, Scottish Government

Minister of Health, Northern Ireland Department of Health

ANNEX A

Reciprocal Healthcare International Negotiations Process Map

Reciprocal Healthcare International Negotiations Process Map



Agenda Item 7

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

Document is Restricted

Evidence Paper

Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

Introduction

1. The Welsh Government welcomes the Committee's inquiry into the impact of waiting times backlog on people in Wales. Waiting times for planned care have lengthened considerably over the last two years and there are now many people waiting longer than we would like for their health care. This is not unique to Wales and can be seen across the four nations of the UK.
2. A clear priority for the NHS as we start to recover is to focus upon reducing waiting times across all specialities. Given the scale of the challenge, it will not be enough to get back to the pre covid-19 activity levels, with some models of care antiquated and unsustainable before the pandemic. NHS Wales has transformed many of its pathways during covid-19 and clinicians have aspirations for further developments and new ways of working. We will seek to embed this in our planning and delivery framework.
3. In the meantime the health service is working in a number of ways, to ensure that there is effective support for patients who are experiencing delays in accessing planned care.

Background

4. In March 2020, in order to support the NHS to prepare for the expected increase in covid-19 cases, a directive was issued to suspend all outpatient and routine planned care activity. Essential services and cancer care continued to be delivered where it was safe and in the best interest of the patient. This was a necessary approach to protect the NHS and meet urgent and emergency covid-19 capacity requirements.
5. During summer 2020, outpatient activity and routine planned care restarted. The infection control requirements to deliver safe services during covid-19 however greatly reduced the productivity of core service activity, resulting in waiting lists and lengths of waits continuing to grow.
6. In 2021, an investment of £248m to increase capacity was provided, and we started to see activity levels rise and mitigate the capacity / demand gap. However, the infrastructure and staffing constraints, together with the continued implications of covid-19 and new variants, have meant that pre covid-19 activity levels could not be achieved.
7. In order to help health boards manage local COVID-19 surges, Welsh Government introduced the Local Choices Framework in December 2020. This framework supports health boards to take immediate decisions about the suspension of local services in response to immediate covid-19 demand. All health boards have utilised this framework as necessary from December 2020 to January 2022.

8. The volume of patients waiting in excess of 36 weeks had reduced to a six year low in March 2019 and the NHS was on track to improve on the position during 2019/20 – however, the start of the covid-19 pandemic significantly impacted on capacity and associated activity levels.
9. Since March 2020 the total waiting list and those waiting over 36 weeks has grown markedly. At the end of November 2021 the total waiting list was just over 682,000 (an increase of 225,500 on March 2020) and the number waiting 36 weeks was 241,700 (an increase of 213,000 on March 2020). The size of the waiting list fell very slightly in November, however it is expected to grow during December and January following decisions to suspend some routine activity in response to covid-19 pressures.
10. Health boards are now working to ensure that their waiting lists are accurate. It is likely that over the last 18 months that some people's conditions and circumstances may have changed. This will not be an exercise of removing genuine patient pathways, but will ensure the waiting lists are correct, enabling health boards to plan effectively.
11. Difficulties with recruitment and retention for many specialities, and particularly rural areas, continues to be a restraint. Whilst increased recruitment and training plans are in place, the impact will not be seen for a number of years. Winter pressures, coupled with the pandemic and the need to support the vaccine programme continues to place further strain on services and staff. Staff have been very hard-pressed coping with the pandemic and need a period of recovery.
12. The focus in Wales is not only to increase capacity, but also to grow our own workforce, making posts retainable and appealing. An example of this working well can be seen through the introduction of new clinical fellow posts within dermatology.
13. To support workforce challenges, an investment of £262m is being made available next year to support education and training programmes for healthcare professionals in Wales. This represents an increase of 15% compared with 2021-22 and will deliver the highest number of healthcare training opportunities in Wales.
14. We will maintain and strengthen investment in education and training of healthcare workers, delivering 12,000 more clinical staff by 2024-25.
15. Significant pressures on the social care system are impacting on timely discharges from hospital and the availability of care at home. We are working closely with health boards and local authorities to monitor impact and promote joined up approaches. Working with health boards, local authorities are increasing investment in social care and we have introduced step down facilities as can be seen in the new developments at Llandudno Hospital. This has been supported by an additional £48m for social care recovery and £42m for winter care pressures to support social care. £10m has also been announced to enable local authorities to make equipment available that supports the independence of people with care and support needs or in an early intervention and prevention context to maintain people in their own homes.
16. Health board's infrastructure is also a key factor impacting upon planned care delivery. National guidance provided during the pandemic clearly indicated the importance of protecting patients from the risk of covid-19 transmission and dividing the estate based on risk of transmission. Some health boards, such as Cardiff and Vale, were able to respond to this. Others struggled as unscheduled care, urgent and planned care are all

delivered on one site. This is particularly relevant with the constraints caused by delayed transfers of care where reduced flow of patients out of hospital, particularly into nursing or residential homes because of restrictions in place due to the pandemic, reduces the flexible use of beds and adds pressure on the estate.

17. Health board estates will need to be used differently in order to respond to the waiting list challenges. More one-stop clinics where patients are seen and treated in a single appointment are required. The introduction of Rapid Diagnosis Clinics are an excellent example of how this can be delivered.

18. The new £50m capital fund for social care includes the development of 50 local community hubs and the strengthening of arrangements to support the integration of health and social care and support the residential care estate.

Plans for addressing the backlog of patients waiting for treatment, including prioritisation of patients/services.

19. The whole solution will need to be a combination of:

- Additional sessional work
- Using the independent sector to deliver activity for NHS patients
- Regional options which will allow protected planned care capacity at a higher volume than traditional hospital based theatres
- Transformation and introduction of new models of care

20. The immediate focus has to be recovery of the waiting list so that we minimise the impact of the pandemic on outcomes and provide timely access of care to those that need it most. This has been set as a priority for the system and will be reflected in health board integrated medium term plans.

21. Over the past year, the national planned care programme has developed a new approach to planned care. The 'Five Goals for Planned Care' have been developed alongside clinical and operational leads. The five goals are effective referral, advice and guidance, treat accordingly, follow up prudently and measure what is important – modernising the clinical model of care.

22. The Clinical Programme for Planned Care covers seven clinical specialities, which are orthopaedics, urology, dermatology, ENT, ophthalmology, general surgery and gynaecology. In November 2022, they account for 65% of the total number of pathways waiting, and 82% of the pathways waiting over 36 weeks. An Outpatient Transformation Programme leading on national work supports the programme.

23. For each of these areas, actions are already in place. For example in orthopaedics, the board is developing a national clinical strategy, there are plans to extend virtual joint clinics and improve MSK management. For urology, the development of a PSA self-management programme alongside improved referral guidance for primary care. A tele-dermoscopy pathway is being developed for dermatology alongside the See-on-Symptom (SOS) and Patient Initiated Follow-Up (PIFU) pathways.

24. This year health boards have been allocated an additional non-recurrent £248m to increase the number of clinical sessions available, increasing activity and mitigating the capacity and demand gap caused by the productivity reduction that covid-19 has brought. There are a number of actions underway ranging from, new modular theatres and additional diagnostic capacity to moves to extend the working day such as a six-day working week for radiotherapy. Health boards have been working to reduce the backlog by using alternative providers, they have used their own staff in local independent facilities, as these are safe green pathways for services and hired mobile units that have been used to carry out a number of day case procedures. The ability to source additional activity has been problematic as organisations from across the United Kingdom are all looking to purchase activity from a small pool of suppliers – hospital estate and workforce availability are key constraints.
25. Health board plans have also included collaborative action between GP practices and community health and care teams to undertake regular reviews and checks for people living with long-term health conditions, such as asthma and diabetes, to help them stay well.
26. From 2022-23 onwards, £170m has been allocated on a recurrent basis specifically for planned care. When combined with the allocations in 2021-22, this will mean a total of £818m will have been allocated towards NHS recovery over 4 of the 5 years of the current Senedd term. This will enable health boards to put some of those staffing plans into place and to develop more sustainable and transformational solutions.
27. We are clear that we will need to deliver services in a different way and are working with the clinical boards to develop sustainable approaches. The national Orthopaedic Clinical Board is currently developing a long-term orthopaedic clinical strategy. In the short term, health boards are looking at regional solutions, and the Welsh Government has invested in two new theatres at Prince Philip hospital in Llanelli. These will deliver up to 4,600 additional day case procedures a year as a dedicated 'green' pathway.
28. Health boards are developing regional approaches for cataracts, with plans to increase capacity in South East across the three health boards. For South West, the plan is to increase capacity at two sites and to share the workforce across the two sites. In the next few months, significant additional capacity for cataracts will be in place in Swansea, Hywel Dda and Cardiff.
29. Betsi Cadwaladr University Health Board is looking at developing regional diagnostic and treatment centres to provide outpatient, cataract services, diagnostics, including endoscopy and inpatient orthopaedics.

The services in place for people who are waiting for diagnostics and treatment, particularly pain management support.

30. Patients are waiting longer across all stages of the pathway, from outpatients, diagnostics, therapy services, mental health support, pain relief and treatment.

Diagnostics

31. The number of patients waiting for a diagnostic test in November 2021 is 106,559, this an increase of 53% since March 2019. Just over 45,500 (43%) patients have been waiting longer than 8 weeks for their diagnostic procedure. This is however a reduction of 15,500 patients from November 2020, highlighting that diagnostic services have been

able to start recovery at a faster rate than that of both outpatient and inpatient procedures.

32. The National Imaging Programme Board and National Endoscopy Programme Board have both evidenced that core demand and capacity has been significantly out of balance even pre COVID-19 given the ever increasing demands for diagnostic testing. This has previously resulted in high levels of outsourced activity, waiting list initiatives and the need for additional or temporary modular facilities. Each Board is supporting local recovery efforts and finalising plans for additional capacity as part of their IMTP submission for 2022/23.

Therapies

33. During the pandemic Allied Health Professions¹ (AHPs) have played a critical role in setting up new and specialist services to contribute to reducing waiting times for patients. These are for patients with persistent pain, vascular presentations, musculoskeletal, orthopaedic and urogynaecological problems as well as signposting to self-management resources.
34. Enabling people to access AHPs directly and earlier in the care pathway can affect demand and reduce disability. 'Prehabilitation' programmes prepare people for surgery and help people remain well while they wait, thus ensuring people are ready for treatment and recover more quickly from that surgery. Prehabilitation and access to rehabilitation and reablement can also enable some people to recover to the point where their need for surgery is less or removed.
35. Services by podiatrists for people with diabetes are helping reduce and avoid amputations. Physiotherapy in orthopaedics and rheumatology can influence the need for more invasive treatment, including surgery.
36. AHPs have been very effective in adopting new ways of working, and they deliver a large proportion of their work virtually. However the combined effect of the additional workload, workforce challenges and patients who are potentially presenting at later stages of their illness, are affecting upon the total numbers and length of waits. In November 2021 there were 56,592 people on the therapy waiting list. Just over 8,350 (15%) patients have been waiting longer than 14 weeks in November 2021 for their therapy intervention. We published our AHP Framework in 2019, supported by £289,681 in 2021-22 and £292,577 in 2022-23 to HEIW to deliver a 2 year National Programme with national clinical leads and models of good practice.

Pain Services

37. In April 2019, Welsh Government published "Living with Persistent Pain in Wales" guidance against which health boards could quality assure the services they were providing.
38. Pain management services have moved virtually where possible and there are a number of services developed on offer throughout Wales to support those living with persistent pain. These include Escape Pain, a group rehabilitation programme with a focus on self-management and coping mechanisms, and Education Programmes for Patients (EPP

¹ 13 individual professions including physiotherapists, occupational therapists, dietitians, podiatrists, psychologists, speech and language therapists.

Cymru), who provide a range of self-management health and wellbeing courses and workshops for people living with a health conditions or for those who care for someone with a health condition.

39. To support a national consistent approach to pain services, we are in the process of appointing two national clinical leads to determine areas of improvement and to help develop future services to meet the growing demand.

Treatment

40. The number of patients waiting for treatment has also grown over the past 21 months. In March 2020, 95,056 patients were waiting at treatment stage (inpatient / daycase), compared to 121,996 in November 2021, a 28% increase.

41. Clinical need, in particular cancer care, has always taken priority on the use of planned care resources. This approach has been the main guiding principle during the pandemic and this has had a significant impact on waiting lists. At present, there is limited capacity available for routine patients for review and/or treatment. Planned care resources are pooled, and available theatre slots are allocated based on clinical risk, with emergency and urgent care taking priority. The Welsh Government role has been to provide national guidance and policy support to ensure safe and effective delivery of NHS and social care during the pandemic. Where appropriate, health boards have been able to adapt and revise guidance based on local risk assessment and resources available.

42. NHS Wales has utilised a risk-based approach to prioritisation for surgical interventions. At the start of the pandemic, the Royal College of Surgeons developed a set of clinical guidelines to aid decision making in terms of surgery with procedures categorised as priority 1 (emergency surgery), priority 2 (operate within a month), priority 3 (operate within 3 months) and priority 4 (operate after 3 months). All health boards took action to maintain elective surgery for the highest risk patients, including cancer (priority 2). Patients assessed, as priority 3 and 4, were determined as clinically less urgent patients waiting for treatment. Cancer services were designated as essential right at the start of the pandemic. We have done all that we can to sustain them throughout the pandemic, but there has inevitably been disruption due to the nature of the waves of new COVID-19 strains.

43. Clinicians have been constantly reviewing their patients on the waiting lists and have reviewed the patient priority at each review ensuring that their priority has been adequately recorded and patients who experience a worsening condition can be treated.

44. In April 2021, NHS Wales agreed on a consistent, national approach to review outpatient waiting lists. The process was developed in collaboration with NHS planned care leads and consultation with the Wales Council for the Blind and Community Health Councils to ensure the accessibility of public-facing resources. The initial purpose of this was to make contact with patients and to reassure them that they were not been forgotten. Secondly, it was to understand the health status of the patient and to determine whether their symptoms have deteriorated which may indicate the need for an earlier appointment. Finally, it was important to determine whether the patient still needed an appointment as they may have had further treatment from primary care, pharmacy or their condition had improved. The first stage of this communication campaign, which started last June, was to write to all patients who have been waiting over 52 weeks for a new outpatient appointment, then those who are waiting for a follow up appointment.

Health boards will use the responses from this communication to prioritise patients through a clinical review.

Access to psychological therapies and emotional support for those who may be experiencing anxiety or distress as a result of long waiting times.

45. Before the pandemic, around one in four people in Wales was experiencing mental health issues. Latest data from Public Health Wales and other surveys show that overall; levels of anxiety within the population remain higher than pre-pandemic. Aspects of personal health and wellbeing, concern about health and wellbeing of others and personal finances have all caused worry for individuals to differing extents over the course of lockdown. A self- management online tool called SilverCloud is available by both self-referral and clinician referral if required. The uptake of this mode of support continues to increase, and is well evaluated.
46. At the onset of the pandemic, additional resources were released to health boards to support the maintenance of essential mental health services while responding to the immediate pandemic pressures. Additional funding for inpatient surge capacity in adult and Children's provision was provided. We have also strengthened the CALL mental health helpline to meet the increased demand and we continue to promote it as one of our key offers. We have also provided funding for a range of regional approaches to reduce suicide and self-harm including bereavement support, training and awareness raising.
47. There are pressures within memory assessment services. To support this a £3m allocated to Regional Partnership Boards (RPBs) was provided, in addition to the £9m allocated at the time of the publication of the Dementia Action Plan, representing a significant increase in funding.
48. We are prioritising mental health across government and investing over £100m of additional funding across the next three years. £90m of that is in the HSS portfolio. (£50m in 22-23 rising to £90m by 24-25).

The contribution the third sector can make in providing peer support and information to patients waiting on an NHS waiting list.

49. Both NHS Wales and the Welsh Government work closely with a range of related third sector partners to support patients and policy development. Third sector organisations such as Cymru Versus Arthritis have created online communities to provide support and offer a wealth of information available on their websites. This includes specific information and advice for those waiting on waiting lists. RNIB Cymru work closely with Welsh Government, they helped to develop a new measure for eye-care, and continue to be pivotal in supporting the health service with clear information to patients. The Cancer Alliance were pivotal in the development of the Suspected Cancer Pathway and constantly hold us to account on cancer performance. There are many examples of the third sector effectively supporting patients alongside health boards.
50. Health board services and websites signpost patients waiting for appropriate support from the third sector. This is an important aspect of the mental health services' approach to supporting patients on waiting lists. Letters sent to patients waiting for treatment include a section on signposting patients to suitable charities and third party bodies.

51. Welsh Government has worked with the British Red Cross on the establishment of a “Waiting Well Support Service”. This service will support patients on waiting lists for elective treatment through the provision of practical and emotional support, signposting and supported referral in order to help people maintain their independence and improve their ability to better self-manage. Four health boards will start to pilot this model for a 12- month period from March 2022.

The effectiveness of messaging and engagement with the public about the demands on the service and the importance of seeking care promptly.

52. In the early part of the pandemic, Welsh Government communications focused upon public health information around the covid-19 risk. This message was provided through national daily briefings, national documents (electronic and paper) and was reinforced by local NHS communication teams. High-level messages around planned care and the impact of covid-19 on waiting lists formed part of these national and local messages.

53. In 2020, Welsh Government procured external communication resources to support the continuing national campaign, “Help us to Help you”. This provided resources to local NHS communication teams to reinforce and adapt national messages to local needs.

54. A list of “staying healthy/keeping well” information links have been developed for health boards to use to signpost patients. The planned care programme in collaboration with the Help Us Help You campaign has developed a series of patient facing videos. These have been used on websites and social media.

55. Health boards have also developed a number of local strategies to support and improve patient communication. Hywel Dda University Health Board, for example has developed a one-point contact for all patient waiting enquiries initially piloted for orthopaedics.

The extent to which inequalities exist in the elective backlog, with deprived areas facing disproportionately large waiting lists per head of population compared to least deprived areas.

56. There is an absolute focus upon health inequalities across Welsh Government. Specific funding is targeted to ensure that this principle is embedded across delivery. We know that the pandemic has affected the inequalities gap, and we are prioritising how we will enable and help to support positive change.

57. Analysis using the Welsh Index of Multiple Deprivation (WIMD) on activity data does not show any significant change in patterns of treatment across the different deprivation groups during COVID-19. It does, as expected, show the general increase in length of waits across each of these groups. Evidence shows that the effect of long waits for people in lower deprivation groups may have proportionally more health consequences due to their existing health issues.

58. More targeted support and signposting to people from deprived areas is required across the whole system to reduce harm while waiting.

59. From a population health perspective, we know that two of the biggest causes of avoidable ill health and death, and drivers of health inequality, are smoking and obesity. Working with health boards, we ensure resources are directed to evidence based interventions. There is additional targeting of these interventions towards groups and communities where tobacco use and obesity prevalence rates are higher, such as more deprived communities.
60. The draft Welsh Government Race Equality Action Plan recognised the unequal impact of the COVID-19 pandemic across certain groups of the population and proposed a specific goal and actions to tackle the health inequalities experienced by Black, Asian and Minority Ethnic people.
61. The consultation on the draft LGBTQ+ Action Plan concluded on 22 October. The draft plan acknowledged the health inequalities experienced by LGBTQ+ people and proposed a range of actions targeted at improving health outcomes of LGBTQ+ people. Work is currently underway to refine the Action Plan in light of consultation responses.

Plans to fully restore planned NHS care in Wales.

62. In March 2020, *Health and Social Care in Wales COVID-19: Looking Forward* was developed that sets out Welsh Government's ambitions and approach to building back our health and care system in Wales, in a way that places fairness and equity at its heart. It builds on key lessons learnt, and describes the opportunities and priorities as we recover from the devastating impacts of the pandemic. It demonstrates our commitment to social partnership, values and expects integration and integrated approaches, and sets out our expectations of delivery.
63. Our intention is to develop a plan to address the waiting times for those patients whose treatment has been delayed by the pandemic. This will be published in April of this year. This will set out our ambitions and priorities for planned care giving a clear steer and direction to the NHS and our partners about our aspirations and expectations for planned care recovery.

Innovations developed to support patients

64. Health and social care services in Wales have been at the forefront of responding to the pandemic. Covid-19 has accelerated change in how health and social care services are delivered.

Supporting Patients

- All health boards have patient support lines in place, and local GPs are aware of their existence. The lines themselves do not all offer direct patient support but they direct patients appropriately depending on the nature of the call. Additionally, the call handlers are able to review current waiting times.
- From January 2022, Cwm Taf Morgannwg University Health Board has an operational Wellness Hub; two of the key programmes on offer are mental health and pain management.
- Cardiff and Vale University Health Board has a number of services and approaches in place to support patients who are waiting to access planned care. Their Prehab2Rehab project promotes an innovative behavioural change approach to health messaging and 'prehabilitation' style advice for patients on the inpatient waiting list. An

important aspect of the Prehab2Rehab project is the <https://keepingmewell.com> website, services signpost patients on waiting lists to resources on this website.

- Orthopaedic patients at the early stages of waiting are contacted to join the 'Living Well' programme which, advises them on pain management through medication and health and wellbeing advice including smoking cessation and dietetics.

Rehabilitation

- A modelling tool to assist in predicting the demand for rehabilitation services supports the Rehabilitation Framework published in May 2020. The Adferiad (Recovery) Programme launched in June 2021 is supported with £5m of additional funding. This programme supports patients experiencing the symptoms associated with long covid. It is supported by a package of comprehensive education and resources. It means that across Wales health professionals have access to the same information and treatment advice on this condition and they have a clear guide on when and how to refer onwards for treatment and support.

Digital

- Significant and accelerated investment in digital technology has enabled rapid service transformation and the continuation of essential services in a safe environment. Attend Anywhere was rolled out at pace to offer virtual appointments across primary, community and secondary care.
- Video group clinics (VGCs) have been introduced, an effective model that allows the clinical team to assess multiple patients together. VGCs are being used in cancer services, mental health, and for life-long conditions such as rheumatology and diabetes and dermatology. Physiotherapist led VGCs are working well in pain management and in cancer services.

Community Provision

- Optometrists are being upskilled to deliver new patient care pathways. The targeted investment for IT, data and digital improvements enables shared care, and enables optometrists to manage and treat more patients in primary care.
- An example of a delivery model ensuring a multi-disciplinary approach is the South West Cardiff Cluster's integrated child health clinic, where outpatient clinics held in GP practices led jointly by a consultant paediatrician and GPs. This model has produced outcomes in terms of reduced waiting times, reduced 'Did Not Attend' rates and reduced need for follow up appointments.
- 17 pharmacies within the Llanelli cluster of Hywel Dda University Health Board will be participating in a 12- month pilot of a Community Pharmacy Mental Health and Wellbeing Service. The service will allow trained pharmacists and pharmacy staff to offer low level Mental Health and Wellbeing signposting support to a targeted group of patients recently prescribed medication for a low-level mental health condition.
- There is a pilot ongoing in Hywel Dda University Health Board, which utilises pharmacy delivery drivers to complete a basic well-being assessment of isolated and potentially vulnerable patients. This pilot currently flags well-being issues with Pembrokeshire Association of Voluntary Services who then raise the need for a review by the GP.
- The reform of the Community Pharmacy Contract Framework means that all community pharmacies in Wales will be able to offer an extended range of services via a national clinical community pharmacy service. From April 2022, the contract will enable all pharmacies to provide treatment for common minor ailments, access to repeat medicines in an emergency, annual flu vaccination, and some forms of emergency and regular contraception.

New Models of Care

- See on symptoms and patient initiated follow up appointments are being implemented across NHS Wales, where safe and appropriate to do so as an alternative to a follow up appointment.
- With support from the Transformation Fund and Integrated Care Fund, Regional Partnership Boards have developed new models of care that have proved invaluable during the COVID-19 response including rapid discharge from hospital to home and admission avoidance models. A new five year 'Health and Social Care Regional Integration Fund' will be launched on the 1st April 2022.

Conclusion

65. NHS Wales has worked extremely hard over the last 20 months to respond to the covid-19 challenge, keeping patients safe and responding effectively to those requiring cancer, urgent and essential care.
66. This response has resulted in waiting times for planned care lengthening considerably over the last two years. Many people are unfortunately waiting longer than we would like for their health care.
67. Our challenge as we move forward is to reduce the size of the overall waiting list and the length of time people are having to wait. This will take time, but there are some excellent examples of clinicians doing this. At the same time we need to ensure that there is effective communication and support for patients whilst they wait.

Health & Social Care Committee Evidence Paper

Health and Social Care Winter Plan 2021-22

1. Purpose

1.1 The Minister for Health & Social Services and the Director General for Health & Social Services and NHS Wales Chief Executive have agreed to attend the Health & Social Care Committee on Thursday 10th February 2022, to provide evidence for the [inquiry into the impact of waiting times backlog on people who are waiting for diagnosis or treatment](#) and to be scrutinised on the Welsh Government's Health and Social Care Winter Plan 2021-22.

1.2 The purpose of this briefing is to provide a summary of the winter planning processes for 2021-22 and an assessment of the assurance provided by the integrated health and social care regional plans undertaken through regional partnership boards.

2. Introduction

2.1 The health and social care system has historically experienced pressure during specific periods of the year, resulting in delays to access that may result in risk of harm, poor experience and quality of care to people accessing services. The winter period, Easter and bank holidays generally present additional challenges to the system when compared with the rest of the year.

2.2 Historically, winter plans have focused on NHS services and have been issued in November, with a requirement for formal submission of plans by health boards and trusts.

2.3 While seasonal planning is not a one-off event and forms part of the requirement of health and social care organisations' operational plans, in view of anticipated heightened pressure resulting from the impacts of the COVID-19 pandemic, a Winter Protection Plan (2020 - 2021) was published by Welsh Government in October 2020. The purpose of this plan was to describe the actions progressed at a national level to enable the health and social care system to deliver safe and effective services throughout the winter period.

2.4 The concern for winter 2021-22 was the impact of multiple risks on an already fragile system. The challenges caused by the pandemic to health and social care staffing capacity; limitations on physical estate capacity associated with streaming of patients and social distancing requirements; increasing activity across urgent and emergency care services; and added complexity of 'new' and latent demand were anticipated as planning commenced for winter preparedness.

2.5 Consequently, a Health and Social Services Group (HSSG) Seasonal Planning Task Group was instituted, chaired by the Deputy Chief Medical Officer for Wales. The group undertook an assessment of the key risks and current mechanisms for providing support to and receiving assurance from health and social care organisations, and identified priority areas for winter resilience.

3. Strategic context

3.1 The Covid-19 pandemic continued to have a significant impact on the ability of the health and social care system to deliver timely and quality care throughout 2021 and urgent and emergency care services came under increasing pressure as the year progressed, due to a number of factors.

- Easing of restrictions on life and increase in transient populations (e.g. tourists) resulting in an increase in presentations to General Medical Services, 111, 999 and Emergency Departments for minor complaints;

- Latent demand caused by initial reluctance amongst the public to seek advice during the first wave of the pandemic, and increasing prevalence of frailty resulting in more people accessing care with complex needs;
- Ongoing infection control requirements reducing physical capacity in Emergency Departments and hospital wards;
- Test Trace and Protect requirements reducing available staff capacity across the system causing delays to access;
- Ongoing primary and community care support for the vaccination programme limiting capacity to manage demand in the community resulting in reliance on 111, 999 and Emergency Departments; and
- Increase in planned care procedures to address the backlog and depleted social care capacity further limiting available bed capacity, causing longer stays and consequences for patients awaiting admission from a hospital bed.
- Impact on the urgent and emergency care system resulting from poor patient flow through the hospital system and out into the community (with long delays for patients awaiting admission to a bed from the Emergency Department, and delays in transferring patients from ambulance vehicles to the care of Emergency Department staff because of a lack of space). This is partially caused by hospital processes and partially by challenges in the domiciliary care and care home sectors.
- Ongoing high demand for domiciliary care for patients in the hospital system, which was forecast by Delivery Unit modelling to extend into autumn 2021.
- Limitations in domiciliary care capacity, which were expected to continue into winter despite concerted efforts to increase recruitment and improve retention in the domiciliary care sector.
- Workforce pressures across the health and social care sector caused by sickness, shielding, staff turnover and fatigue of staff who have worked through a protracted period of heightened pressure.

4. Health and Social Care winter plan intent/purpose

4.1 The Health and Social Care Winter Plan 2021-22 was developed to address the composite risks to patient safety, with the primary aims of keeping the population safe from COVID-19 and safeguarding health and social care services for people most in need.

4.2 The purpose of the Health and Social Care Winter Plan was to describe the actions being taken nationally to support health and social care organisations to plan for the winter period, and to set out priorities for regional partnership boards, local authorities, health boards and NHS trusts. Assurance was required from organisations that their plans were sufficiently robust to ensure they maintain key services for the people of Wales during the winter, and to keep Wales safe.

4.3 The expectation of the plan was for health and social care organisations to strengthen their winter plans through collaboration. Regional Partnership Boards were asked to lead the development of high level local integrated plans that described how partners were working together to deliver on agreed priorities for winter, as part of ongoing activity to maintain services and address system pressures.

4.4 In seeking to respond to the five harms associated with the pandemic¹, the plan set out eight priority areas to keep people safe and reduce risk of harm. The eight priority areas were:

- Protecting us from COVID-19
- Keeping people well
- Maintaining safe health services (planned and urgent and emergency care)
- Maintaining our social care services
- Supporting our health and social care workforce
- Supporting unpaid carers
- Keeping everyone informed
- Working together across Wales

5. Financial support

5.1 During 2021, alongside an ongoing package of financial support for NHS response to COVID-19, more than £200million revenue and £48m capital was invested in supporting and accelerating the recovery of planned care services across Wales to ensure that people have their assessment and treatment as quickly as possible.

5.2 £25million recurrent funding was allocated to support the delivery of the Six Goals for Urgent and Emergency Care, focusing on four priority areas:

- Implementation of urgent primary care centres across Wales to better manage demand in the community.
- Roll out of 111 nationally and an increase in the number of clinicians to provide remote advice / assessment and signposting.
- Establishment of robust same day emergency care services to help avoid admissions to hospital.
- Implementation of discharge to assess pathways intended to avoid admission and speed up discharge to a person's usual place of residence.

5.3 A further £2.26million was invested in non-urgent patient transport, in an effort to ease pressure on ambulance services and ensure patients can continue having access to planned care.

5.4 £40million was allocated to support recovery of social care services aligned with the Social Care Recovery Framework.

5.5 In addition to these investments, a further £9.8million was allocated to regional partnership boards (RPs) on 26th October 2021, to support delivery against the priorities set out in the winter plan, alongside a further £32.92million for social care pressures.

6. Associated guidance documents

¹ The Five Harms: Harm from COVID-19, harm from an overwhelmed health and social care system, harm from reduced non-COVID activity, harm from wider societal actions (lockdowns, etc.), harm from new or existing inequalities either directly or indirectly from COVID-19

6.1 The winter plan was issued within the context of a number of other key guidance documents with a specific focus on address key factors impacting on seasonal pressures.

6.2 A Local Choices Framework, issued in December 2020, provides NHS organisations with permission to make local choices, in a local context and informed by local engagement to flex service provision and to redeploy staff to respond to exceptional demand. This has been reviewed and was re-issued to Health Boards on 1st October 2021.

6.3 The Coronavirus Control Plan sets out Welsh Government's wider response to Coronavirus and provides the wider context to this health and social care plan. The Coronavirus Control Plan: autumn and winter update was issued on 8th October 2021.

6.4 The Public Health Response to Respiratory Illness Winter 2021 sets out the detailed response to both COVID-19 and seasonal influenza and was published on 21st October 2021.

7. Winter planning and delivery assurance mechanisms / governance

7.1 All RPB statements of assurance/ winter plan documents were submitted by the end of November 2021 and were reviewed by policy leads across the Health and Social Services Group. Initial feedback was provided verbally on 7th December to RPB leads. This was followed by written feedback from Welsh Government officials on 13th December, which identified supplementary areas requiring assurance. The plans and associated risks/issues are also subject to regular discussion at meetings, supplemented by written feedback. Further formal written feedback was issued to RPBs and their constituent partners on 18th January 2022.

7.2 In addition to the processes for the plans themselves, there are a number of other mechanisms for providing support and seeking assurance on delivery of winter plans to maintain safe delivery of health and social care services.

7.2.1 Winter planning and resilience is a standing agenda item on the Integrated Quality Planning and Delivery meetings between Welsh Government officials and health boards and trusts. These are held on a bi-monthly basis.

7.2.2 System resilience meetings have been put in place for health boards and NHS trusts. Meetings were held in October and December 2021 each health board and NHS trust, and subsequently weekly reports are submitted to Welsh Government which set out risks and action in mitigation, including the deployment of action within the Local Choices Framework.

7.2.3 The COVID-19 Planning and Response Cell continues to meet weekly with representation of Welsh Government and health and social care organisation representatives. Operational pressures and system resilience is a standing agenda item.

7.2.4 During November and December Welsh NHS organisations were asked to supply further assurance on their operational plans to maintain patient safety and key services for the two-week festive period including Christmas and the New Year. Submissions were mapped against nine priority areas and RAG rated in a summary document, which was retained as a live document with further updates until the commencement of the festive period.

8. Evaluation and learning of winter planning and delivery

8.1 Formal review of the action funded by expenditure of the allocations to RPBs from the £9.8m winter funding is being undertaken through expansion of existing reporting processes designed for activity supported by the Integrated Care Fund.

8.2 A wider review and evaluation of winter arrangements will be undertaken, drawing on these formal monitoring processes and regular feedback mechanisms and will seek to identify and learn from areas of notable practice in addition to the challenges experienced by RPBs in implementing plans.

Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

Engagement Findings

January 2022

In November 2021 the Senedd's Health and Social Care Committee launched an inquiry into the 'Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment'.

The Citizen Engagement Team supported the Committee by facilitating a series of interviews and focus groups with people who are currently, or have previously been, waiting for diagnosis or treatment. This report summarises the Citizen Engagement Team's findings.

Engagement

The Citizen Engagement Team conducted a series of 13 interviews between 4 November and 22 December 2021.

The objective of these in-depth interviews was to gather the views and experiences of people across Wales who have been impacted by the waiting times backlog.

In addition to the 13 interviews, two focus groups were conducted. These were arranged in partnership with Fair Treatment for the Women of Wales (FTWW) which took place on 5 and 6 January 2022 and were attended by Committee members Rhun ap Iorwerth MS and Mike Hedges MS.

Participants

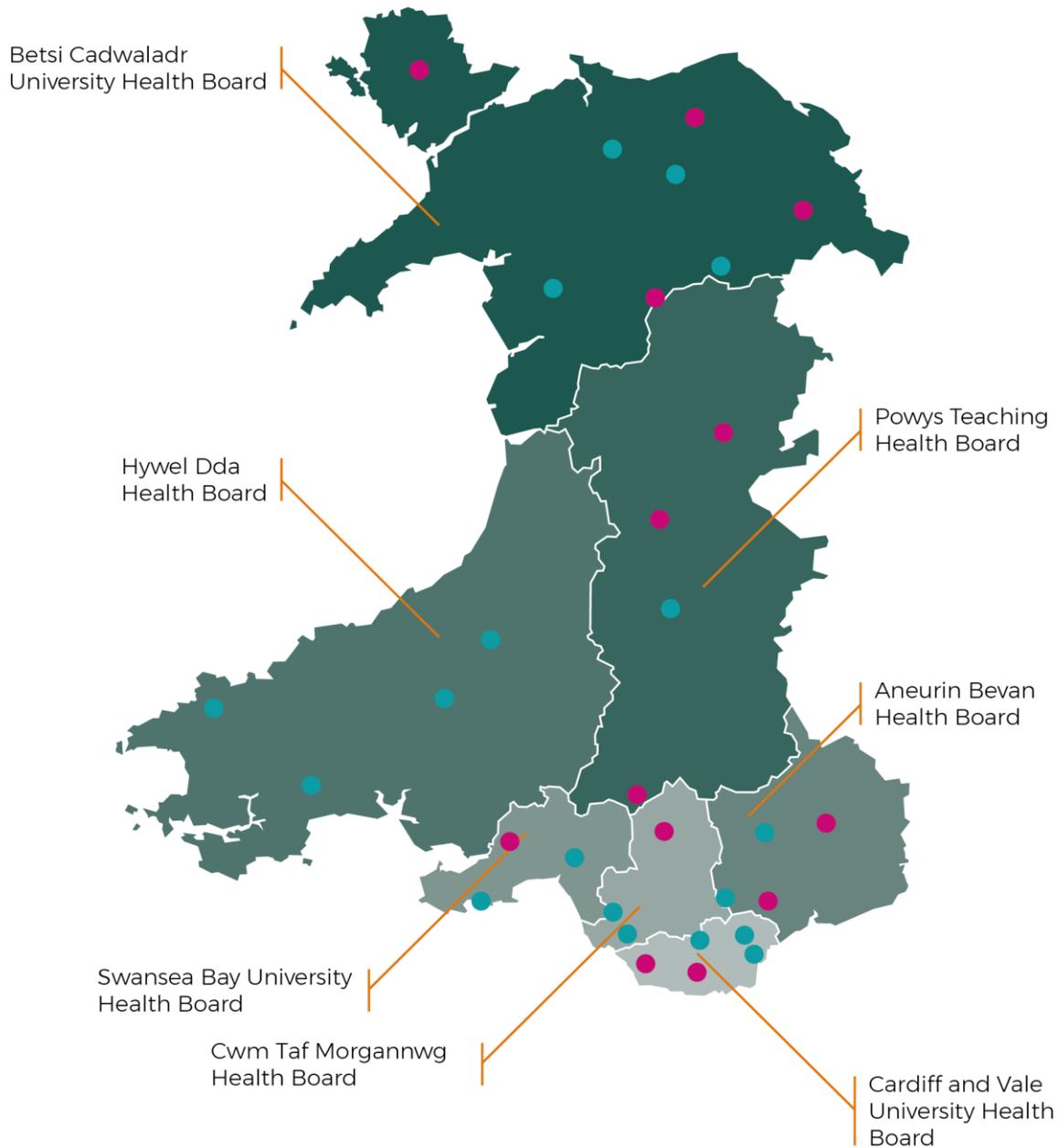
The Citizen Engagement Team worked in partnership with relevant organisations to identify participants and ensure that they received appropriate support and advice throughout. This included some organisations that had identified waiting times as key priorities in their responses to the Health and Social Care Committee's [consultation on priorities for the Sixth Senedd](#). Efforts were made in partnership with relevant organisations to ensure that participants were located across different health boards in Wales and had a fair male/female balance. Ages of participants varied between 23 and 83.

All case studies have been anonymised.

Partner organisations

- Age Cymru
- Carers Wales
- Cymru Versus Arthritis
- Endometriosis UK
- Epilepsy Action Cymru
- Diabetes UK,
- Fair Treatment for the Women of Wales (FTWW)
- Mind Cymru
- MS Society

Location of participants:



● Focus Group Participants

● Individual Interviewees

Thank you to everyone who contributed to the programme of engagement.

Methodology

Interviews were held over the phone and via Zoom and Microsoft Teams in English. The format of engagement was largely comparable between sessions but varied slightly to meet participants' needs and facilitate organic, qualitative conversations.

The following questions were used to prompt interviewees:

- What help have you received from the NHS to help you manage your condition and pain related to it while you waited for treatment?
- What type of support were you offered, such as referral to the third sector, physiotherapists, occupational therapy, prescription or over-the-counter medication, mental health support?
- Have you been able to access this support?
- Have you had to access GP or A&E services for support for the condition you are awaiting treatment for?
- How easy has it been to access information on how to manage the pain and symptoms?
- What communication have you received from the hospital and clinician?
- Have you been able to easily access information about where you are on the waiting list?
- Have you or are you considering private healthcare?
- What are your concerns and how do you think your experience could be improved?

Summary of findings

Each interviewee raised specific issues relating to their own circumstances. However, a number of key themes emerged across the interviews, and across different health boards and medical conditions. Quotations relevant to these themes can be seen in the individual case studies.

Key themes included:

- Participants were consistent in the view that **communication** problems had been exacerbated due to Covid-19.
- Participants noted key **inequalities** that affected their ability to receive care. This included geographical inequalities and financial inequalities.

- Multiple participants indicated a **lack of NHS support** to help manage their conditions, including pain management support and mental health support.
- Participants indicated several examples of problems with regard to **referrals** to neighbouring health boards and also cross-border referrals .
- Several participants have either explored the possibilities or had **private treatment** due to the length of waiting times
- Participants brought up wider **systematic issues** within the NHS which played a role in longer waiting times, including poor health board collaboration.
- Participants noted that early **misdiagnosis and lack of knowledge** within the NHS of certain conditions, caused much longer waiting times and poorer experiences for patients.
- Participants noted that there was a reliance on **third sector organisations** to provide the support for patients on waiting lists that should be provided by the NHS

Case Studies

Participant A

Age: 82

Sex: Female

Health Board: Cwm Taf Morgannwg University Health Board

Key themes:

- Quality of life being affected
- Frustration leading to exploring options for private treatment
- Poor communication during Covid-19

Background:

Participant A noted that as an active older person, the impact of being on a waiting list has affected their confidence and quality of life. An issue affecting her eyes developed in 2017, after a routine visit to her opticians identified that she was slowly developing cataracts.

"I am a very active pensioner, I like to have my independence, I used to drive down to see my daughter and now it's just not possible. I do still drive but driving in the dark or in bad weather is now a big safety risk for me and others. Reading is very difficult; I can't make out numbers and I have found myself just not going out as much as I used to. I have to rely more on friends and family – I have lost my independence."

Participant A explained that a referral was initially made to the NHS in the winter of 2019 and that no follow-up correspondence was received.

"I did have an initial letter in 2020 to confirm that I was on the waiting list... since then, nothing ... it's a shambles really."

Participant A is clear that she believes Covid-19 may have had a detrimental impact on the quality of service she received, in particular relating to communications.

"I had no contact since January 2020 from the NHS. I have tried to chase them up on 3 separate occasions; the phone kept ringing. 6 weeks ago, I finally managed to speak to someone. I was told the waiting time was 27 months from time of referral. I am now waiting for next steps, I am not holding my breath."

Participant A explained how the situation has got to such a point where going private had now become a real option, despite the financial difficulties that would present. She did not feel that waiting a further 27 months was an option.

"The only way I could do it (go private) is potentially going and dipping into my savings. I have a small NHS pension having worked with the NHS all of my life. It's a bit disappointing than when you need something you can't get it after giving your whole life to the NHS."

Conclusions:

Whilst acknowledging the impact of Covid-19, Participant A was extremely frustrated with the lack of communication from the health board. She pointed out that she was extremely proactive and that she knew of others with similar issues that are going unnoticed.

"Communication doesn't have to be over-bearing. It's not asking for much, even if we were given an update once every 6 months, even once a year! It would make you feel that you haven't been forgotten about."

Participant B

Age: 79

Sex: Male

Health Board: Betsi Cadwaladr University Health Board

Key Themes:

- Poor communications
- Frustration and pain led to seeking private treatment
- Lack of advice and support from health board about pain management
- Difficulties around cross-border referrals

Background:

Participant B previously underwent surgery in 2016 for a hip replacement at which point he was advised by the surgeon that he would need to replace the other hip soon. This initial surgery took place in England, and he stated that everything ran smoothly from the initial referral to the surgery itself. According to Participant B his experience changed in 2018 when his other hip started to cause issues.

"It was 2018 when I started having pain in my left knee. After X-rays showed nothing, the GP said it could be the left hip which wasn't a huge surprise. I was prescribed painkillers and sent to a musculoskeletal clinic. This was a complete and utter waste of time, and I was sent back to the GP utterly pissed off. I asked them why I simply couldn't see the same surgeon as I did in 2016 over the border and was told that "Gobowen (Hospital) is a dirty word as far as Betsi Cadwaladr is concerned"."

Participant B notes that things did not get any easier over the next 12 months. Multiple trips back and forth between the GP and physio took place before he was diagnosed as having a clear issue with the hip and referred to a consultant in August 2019.

"After referral in August 2019, I didn't hear anything for the rest of the year. Eventually after chasing and chasing, I managed to make sense that I was on a waiting list. Finally had a call from a knee surgeon at the start of 2020 who told me nothing was wrong with my knee but my hip was in a bad state. This was something I already knew years ago! By this point I was in excruciating pain, walking with a stick and my quality of life had decreased dramatically. I was told then - even after the confusion around my diagnosis - that the NHS waiting list was 3 years and rising. I had no option then but to go private."

Participant B had private surgery in 2021 and stated that he made this decision as a result of huge frustration, the deterioration of his quality of life and the prospect of another 3 years of waiting.

Conclusions:

"There desperately needs to be better communications, a phone call, a questionnaire. Some people might not suffer so much and others have issues that really negatively affect their life. There is just no contact from the health board. The GP knew I was paying for private physio and encouraged me to continue down that path: 'Lord knows when you'll get dealt with here'. The fact that you are on a list with 3 years plus is one thing but the non communication is infuriating. I could do nothing else. I felt left by the wayside, and I am one of the fortunate ones."

Participant C

Age: 21

Sex: Female

Health Board: Betsi Cadwaladr University Health Board

Key Themes:

- Poor communication between health board and patient
- Poor internal communication between therapists and doctors
- Negative impact of Covid-19 on Mental Health Services
- Lack of support from health board in suggesting different services available, for example the third sector.

Background:

Participant C first contacted the NHS while she was in school, and her experience has been varied over the intervening years with the Covid-19 pandemic having an impact on NHS Mental Health waiting times and services.

"I didn't know what mental health was. I felt very quiet and regressed. My parents noticed this and put me into CAMHS (Child and Adolescent Mental Health Services) at 15 before I transferred to Adult Services. I found the initial stage hard, learning about what mental health was at a tough time for me with school."

Participant C has seen a huge change in the service over the last few years as she transitioned from CAMHS to Adult Services. She stated how her situation has gone

from bad to worse over the last 10 years and points to possible systemic issues and poor communication playing a part in this.

"I hardly see my mental health therapists anymore. I get no communication, only the odd letter about blood tests. I used to have weekly therapy support and then it disappeared and went non-existent. I feel sorry for anyone coming into this system during the last 2 years.

Communication has been dreadful in the last few years; I was introduced to different therapy and emotional support when I was younger and in all honesty, I couldn't fault them. Now it feels very different. Covid has had a huge impact on Mental Health services – you are the one doing the chasing all the time. I just feel like garbage!

The health board needs to sort out their working system. The communication between therapists and doctors seems horrendous – you end up getting promised referrals and then nothing happens. You end up thinking – why are they lying to you?"

Participant C mentioned the benefits of having strong support from Mind Cymru but that she had to research any external support herself and never got any referral or suggestions from the health board.

"I read up on Mind and only realised then that there are people like me – Mind is keeping me busy and positive. I have been supported by Mind for 3 years and the support of the third sector is so important.

They fill a role that the NHS isn't. With the NHS you are the one chasing, calling, trying to make an appointment, trying to help yourself and then just waiting... weeks... months... years... for a response."

In July 2021, Participant C received a letter from the NHS to explain that she had been discharged from the NHS Mental Health services they were already accessing without any specific reason given.

"I opened the letter, and I am still shocked today. I couldn't get an answer why they had discharged me. I thought I was just garbage – I really felt low.

My Mental Health that I have struggled with for a decade went downhill, it was an awful feeling.

After that letter, I had to consider going private – my parents saw it in my face that I was broken and disappointed. I have been looking at private clinics, got to the point of no return with the NHS."

Conclusions:

"The NHS staff work hard; we know this but we desperately need more expertise, we need more therapists. Communication both internally and to patients needs improvement. Covid hasn't helped but it was an issue before that as well."

Participant D:

Age: 65

Sex: Female

Health Board: Swansea Bay University Health Board

Key themes:

- Misdiagnosis and mis-referrals.
- Poor communication from health board around waiting list times.
- Lack of support from NHS to manage situation.
- Poor mental health and deteriorating quality of life due to waiting.
- Forced to seek private treatment abroad.

Background:

Participant D had a history of surgeries before being sent to a hip consultation in 2017. She notes that 4 years of misdiagnosis and poor communication with the health board led to an extreme deterioration in her quality of life, poor mental health and ultimately left her feeling like she had no option but to travel abroad to seek private surgery.

"My 2017 consultancy was very dismissive. The diagnosis and the X-ray didn't match the pain. Eventually the NHS suggested an injection into my hip which didn't work. I went back and forth between referrals to the spinal team, then back to the hip consultant. It was July 2021 that I finally saw a hip consultant and was put on a list."

By July 2020 Participant D was in a lot of pain, walking with two sticks and totally deflated. She mentions that in the years leading up to 2021, the support she received from the NHS was minimal with the focus being on rest, and the lack of support led her to visiting a private physio which improved her movements.

"I know there was a long waiting list, but it wasn't until September 2021 that I was put on one. No-one had even mentioned waiting lists to me until this point, but I knew they

were long by conversations I had with friends. I was told then that the waiting time at that point was 3 years... most likely 5. It was at this point, (and I don't cry easily) that I burst into tears. I am 65 and can barely walk no so what am I going to be like by the time I get an operation.

The feeling I got then was that they were happy to leave me for 3 years and just let me rot away in the corner."

By this point Participant D had started doing some research about private hip replacements. In the UK, she had seen quotes of £15-17k for two days of hospital care and no aftercare which was beyond her financial capabilities, so she started looking for options abroad.

"I saw an advertisement...it looked incredible. I did my own research including joining an online support group and talked to someone local who had it done and was very happy with the experience.

In my meeting with the doctor he asked, 'have you thought about going private'. I explained that I had but UK was too expensive and said I had looked abroad. After finding out where – his reaction was 'I have been there – If I were you, I would explore that opportunity'. It could be years and years before you get seen here.

I eventually booked, and stayed there for a fortnight to recover as well. Including flights, insurance, rehab and hotel for me and my husband it was £8k, that included a couple of G and Ts. Half the price of just the surgery in the UK.

I feel and look 10 years younger – I felt a grey shadow of myself with all the pain and the waiting. My Mental health was in a terrible place. Why can't the NHS pay or part fund people to go abroad? It makes no sense that for £10k cheaper I can travel abroad, get the procedure done and recuperate than I can get it done in the UK."

Conclusions:

"I am frustrated. Communication was awful – there could be some easy comms in place to keep people updated, and maybe suggest some places for help, third sector orgs or support groups. I am used to communicating with people in my professional life. I just didn't get anywhere when I tried. You felt dumped and for some people that is going to be a big problem. You gradually and gradually sink a little bit lower each time, left in utter limbo."

Participant E

Age: 83

Sex: Male

Health Board: Powys Teaching Health Board

Key Themes:

- Lack of communication and updates from NHS
- Covid-19 a clear distraction for NHS
- Waiting times leading to poor quality of life
- Significant impact on mental health
- Inequality around access of private surgery

Background:

Participant E first started having problems with his hip in 2018 before he was quickly referred to a consultant by his GP. He was put on a waiting list in the early part of 2019 and whilst he was not told any specifics around the time he might be waiting, from his own research he realised it would not be imminent.

"I didn't hear anything until 2020 – the consultant called me in and said: 'I can offer a steroid injection, but if I do and you take it then your place in the queue will be rock bottom as the health board will deem it as you have been seen to'. I was told that it wouldn't cure the problem but could alleviate the pain. I had no other constructive piece of advice from the NHS during this period"

Early in 2021 I was called by the hospital and again asked if I would like a steroid injection. I noted what I told the surgeon that I didn't want to be put in the back of the queue. A couple of days later, I received another call which said I had now been moved from the routine list to the urgent list. I thought 'that's progress'. Later in the year, I had 2 further appointments and thought things were moving on as they were taking an active interest."

Participant E notes that he heard no more from the NHS following these appointments, even after chasing up on two separate occasions. He now feels that his condition has deteriorated, and pain increased which has led to a much poorer quality of life, poor mental health and an overall lack of confidence.

"I have to say that since Christmas, my hopes and aspirations have taken a nosedive. I know my condition has deteriorated, I now have to walk across the house with a walking stick. The pain is constant and getting to the point where even making a cup of tea is a physical and mental effort."

It might sound melodramatic, but I am 83 now and in two years time I will be 85 – I don't think I want to go on as I am. I am on my own, I am weary of it all – if I reach 85 and nothing will have been done then I don't know if I will be able to go on. I have lost my confidence to go out of the door.

It's not just a physical problem that I have, it's a mental one as well. I'm taking a step back from everything. I'm in here and the world is out there, and I get angry with myself, I get cross with the situation as it stands."

Conclusions:

"During Covid the communications have been non-existent, nothing at all – I have made 1 or 2 approaches to the surgery to see if I could make sense of it, but they are not prepared to tell me anything.

If someone could give me an idea of a date, then I could look forward to it. If nothing happens in 2 years, then I am just going to give up'.

I have thought about going private, but the cost is so prohibitive, £14-15k – I don't have that money. It's a nice thought but not realistic, it's just an unfair system, just not viable."

Participant F

Age: 40

Sex: Female

Health Board: Aneurin Bevan University Health Board

Key themes:

- Long waiting lists at a crucial development stage
- Poor diagnosis from NHS specialists leading to longer waiting times
- Mental health impact on carers of people on waiting lists
- Covid-19 having a negative effect on communications although pre-pandemic communication was also poor.

Background:

Participant F is a carer for their 5-year-old. Her child has had extensive stomach issues since birth with the lack of diagnosis an issue. Alongside the stomach concerns

her son was also on a waiting list for an ear, nose and throat specialist appointment and been diagnosed as autistic.

"Things came to a head in 2019/2020 – when he went to nursery and it transpired he was spending most of his time there lying on his stomach. He was just miserable. Around that point we realised there was a major problem with his stomach. We were already under a paediatrician, being investigated for global delay/sleep problems and for ENT problems

The doctors were very poor – they had no idea what to do with him and having different 'treatments' didn't work. The guidance from our paediatrician was sketchy at best.

I thought the communication was poor leading up to Covid; we would get some calls and the odd face-to-face interaction. Covid meant things just got so much worse. The only reason we had any comms was because I would have been ringing them up and shaking them like a tree. I am a second gen carer so I know you have to chase appointments."

Participant F also explained their worries that long waiting times for a referral to an ear, nose and throat specialist during such a crucial development stage of life could have had a negative impact on their son's development.

"I feel it's wasted time. 2 years of vital time between 2 and 4 and we were just on a waiting list. We were 2 years on the ENT waiting list before we finally got the appointment (after a cancelled one due to Covid). We found out that he was going deaf on one side, and this was then affecting his speech. If we had known this two years ago, we could have done something different about it."

As well as obvious issues for her son, the impact his health and the relationship with the NHS had on the carer and family has been difficult.

"It's been intense – watching him in pain is hard work. Not feeling like I was being taken seriously earlier makes me angry. It felt like they were kicking the can down the road. It's negatively affected our quality of life – it's mentally and physically exhausting."

Conclusions:

"With better diagnosis it feels like waiting times could improve in some areas. Until we figure it out it takes longer and longer to get to the solution."

We are still in touch with NHS as my child has multiple issues. Whilst it's wonderful that he finally seems to be getting better, the lack of diagnosis two years ago is frustrating – so it's a conflicted feeling of elation."

Participant G

Age: 40

Sex: Female

Health Board: Powys Teaching Health Board

Key themes:

- Mental health of carer and family
- Terrible cross-border communication
- Inequalities of access in Wales
- Lack of specialists and knowledge within the health board
- Poor support from NHS for managing the conditions and accessing support
- Positive support from third sector

Background:

Participant G is a carer for her son who has chronic health problems. Participant G notes that her child's health issues over the last 15 years, coupled with negative experiences with the health board has caused huge pressures on the entire family.

Since October 2021 the child has been moved to a specialist unit in England, which means that Participant G travels 120 miles whilst sharing caring responsibilities with her partner.

"We were admitted to Telford Princess Royal Hospital on the 22nd of September where my child was presenting a slight jaundice and an increasing itch.

This escalated during the 3 weeks in Telford, where he scratched the skin off his feet, he was toxic yellow, very confused and he had an internal bleed and was dying in front of our eyes.

He went into kidney failure due to the liver and length of time he had to wait, 11 weeks!

His paediatrician and his team were literally fighting to get a bed for my son on a specialised liver unit, they are general paediatric unit and not able to save my son.

It took three weeks until we finally arrived at QE Birmingham where we were told he was very poorly, he wouldn't be going home and that he needed a liver transplant.

On the 11th of December he had his life saving liver transplant. On the 25th of December he had surgery as he had a blockage and needed corrective surgery."

Participant G highlights the that access to specialist services is dependent on where you live in Wales.

"Living rurally means we have never been offered the choice in Wales. We were told, 'oh well what do you expect us to do, pick up the hospital and move it to you?' Geographically we are not in a good place to be in."

Another key message coming from Participant G is the impact this had on the family, with support coming not from the NHS or the Welsh Government but from the third sector, with 'Carers Wales' in particular providing invaluable support. She specifies the PTSD the entire family have experienced and the decline in her own mental health.

"We needed better communication with me and better communication between hospital and GP. More help needs to be available to manage the condition and additional signposting to services that may be able to offer help."

Conclusions:

"The dynamics of where we live in good old Powys, no man's land in regard to health and services means we have such an inequality of services.

My son nearly died and the trauma of this has and will never leave us. My son has PTSD and it has been suggested by a psychologist I'm showing signs of trauma. We are three months into our hospital stay, my husband and myself share care at his bedside, travelling 120 miles back and forth to the hospital. It's financially a strain for both of us on the sick on reduced pay. It's an emotional rollercoaster.

I am concerned that my child's condition will get worse, his pain condition worsens, he will have a longer recovery time and condition will become permanent due to the damage caused by not having treatment in a timely manner.

NHS management need to be accountable and politicians need to be accountable for a system that takes our money and pays their wages but is not delivering the service. People are dying and someone needs to answer for this."

Participant H

Age: 58

Sex: Male

Health Board: Betsi Cadwaladr University Health Board

Key themes:

- Poor communication
- Impact of Covid-19 on communication
- Seeking private treatment

Background:

Participant H is a chemically induced diabetic due to having had bowel cancer three times. Whilst the diabetes was initially under control with medication following a referral within the health board, he states that things got progressively worse. One of the main issues was the impact that diabetes was having on the participant's sight.

"In 2017 I detected there was a problem with my glasses, so I got monitored every 6 months instead of 12. A consultant said I needed to start a period of treatment involving an injection into one eye and laser treatment on the other. It was January 2019 when I had the first ones, then lockdown started. I had another injection and no treatment on the left eye. Usual comms went down, 6 months later, no contact, no response. I eventually got back in touch with an appointment clerk in early 2021, only to be told I had missed an appointment, which was never the case..."

Participant H explained how there was a marked dip in communication once Covid-19 arrived and caused additional stress to the health board.

"Everything seemed to stop dead – the missed appointment with a letter that never existed, I never received it, first I knew of it was when I phoned up to check a whole three months after this so-called missed appointment.

After that last eye injection, it was like I didn't exist anymore, there was no guidance on how long I would have to wait.

If I hadn't gone private by going to the optometrist then we would be having a different conversation"

Conclusions:

"It did feel like a perfect storm. I have sympathy with the NHS with the conditions they were working in. I am probably more easy-going as I have such admiration for the NHS, but simple things like improving patient communications would help the experience so much"

I am also under oral health dental hospital in Liverpool and the way I get treated over the border has been totally different, the communication there has been immaculate and video calls have been great."

Participant I

Age: 49

Sex: Female

Health Board: Aneurin Bevan University Health Board

Key Issues emerging:

- Covid-19 affecting communication
- Lack of signposting to support
- Need for regular checks for key conditions
- Poor support in diagnosis stage
- Positive support from the third sector

Background:

Participant I was first diagnosed with type 2 diabetes 7 years ago where she recalls the poor support she received initially. Participant I notes that a lack of support is consistent in her experience, with a dip in communication during Covid-19 being very apparent leading to crucial appointments being cancelled.

"The nature of diabetes is that it gets worse – it's a progressive condition. It can attack nerve endings, in ears/eyes/fingers/toes. It is important that regular checks take place. During the pandemic everything stopped and diabetic specialist nurses were deployed to the front line, nothing there for you. You could try to ring, and the phone just kept ringing and ringing, you felt abandoned. There was no communication.

Care is now mostly through hospital, but annual check is at the doctor and is supposed to be once a year minimum, it's regularly cancelled."

Participant I also notes that the NHS's lack of knowledge and support when dealing with diabetes symptoms is a clear issue and leads to people having to find out their own answers online.

"More support in the NHS would stop this from happening. I had a 6-month review and that was it. I should have been referred to the eye screening service and an education course, they would need to do a foot check, but it was not explained properly, and it was a big concern for me.

I came across Diabetes UK and started a local group in Newport. The checks were really poor and some of the comments from the group were staggered about the poor service they were getting and the poor checks (not even taking shoes off for foot checks).

I find that I was doing the job of the GP and health board to support people with diabetes in the area. I went to tell all the GP practices I was there for support via Diabetes UK – please use us to signpost people but only 1 GP took it up."

Conclusions:

"I think the retinopathy service needs to be looked at. It can happen so quickly that it creeps up on you and not having regular checks is a massive issue. If it gets caught early enough then it can be treated. In my opinion eye service and eye screening is a huge issue.

Psychological support needs to be improved for diabetes care as well. They do it so well with care plans for other conditions and issues – but so poor with this condition. Over last 8 months my dad has been diagnosed with cancer – and the service from the cancer team has been incredible – so it's not all bad.

People are fed up with waiting – and pick up information that might be wrong and scare monger off Google. How do you put a measure on somebody's quality of life?"

Participant J

Age: 34

Sex: Female

Health Board: Powys Teaching Health Board

Key Themes:

- Lack of general NHS knowledge around endometriosis
- Good support from endometriosis nurse
- Covid-19 impact on communication
- Inequalities of geography

Background:

Participant J was diagnosed with endometriosis recently but believes that she has actually had endometriosis for 17 years. Following initial surgery in May 2019 she was referred to a specialist in Cardiff.

"I sort of knew I had this since 14 but not diagnosed 'til I was 31. I read an article in the Western Mail which showed the symptoms. I went back with this article and the GP agreed and referred me to a gynaecologist...first time I have ever been referred.

So, I had an initial operation in May 2019, and it was then I was referred to Cardiff because that's where the endometriosis specialists are because I have pretty severe endometriosis. I was told, then there would be a bit of a wait, and that was obviously pre-Covid."

Participant J is clear that they believed there was clear lack of knowledge from her GP and the wider NHS around endometriosis, and it was not until her first meeting with the endometriosis nurse that she managed to get some information which helped.

"In January I had an appointment with my endo nurse – this is where I got some really good suggestions as to how to manage the pain, something that GPs etc in the past have never even mentioned. I learnt more from this half hour with the endo nurse than with 17 years' worth of GPs. In that appointment I was put on a surgery list, then told it was a potential 2 year wait, I was just happy to be on the list."

Participant J noted that the impact of Covid-19 on both the communication and service she received was immediate.

"2 months later Covid hit, and everything was cancelled I wasn't worrying too much about that initially. I had no update, the only news I would get was in a Facebook group I was part of – word of mouth from others who had some discussion with the hospital. In April I rang Cardiff and was told there was no surgery until at least 2020.

Eventually I got a follow-up call later in the year from a nurse – I was on Prostag injections and the side effects were very bad. I was supposed to be taking them until my operation but now there was no end date I had to go to the GP.

I rang the hospital again in January 2021. They didn't have much of an idea but was given an indicator that I was in the top 40 in the list out of 200 plus and should hear soon. Nothing again so rang again in April and was told everything was shut again"

Conclusions:

"Up to Covid I found comms quite good to be fair, I don't like to bother people – I tended to email asking a few questions and I would get a reply. The endo nurse email was very useful – having a direct contact made a huge difference I think without those direct contacts I would be in limbo.

Before my official diagnosis I was being tested for everything. I feel there's a real knowledge gap here around endometriosis. Felt like I was the expert not the health professional...

I definitely encountered some inequalities around geography. I think people need to know their pathways, what is the referral map? Where do I go? Are waiting times big? Should I be chasing things up?"

Participant K

Age: 28

Sex: Female

Health Board: Cardiff and Vale University Health Board

Key themes :

- Lack of support from NHS to manage condition
- Lack of knowledge of endometriosis
- Effect on family
- Positive support from third sector

Background:

Participant K was initially diagnosed with endometriosis at 17 years old and mentions that it was only due to her mother advocating on her behalf at this age, that she was diagnosed this early, which she finds lucky in that regard. She spoke in-depth about the struggles she faced when trying to escalate the issue within the NHS.

"I've got an NHS appointment next week with the endometriosis specialist in Cardiff. But I had to pay to see this same specialist in private last year as a one-off thing. This was because I'd been telling my general NHS gynaecologist for 10 years about my bowel symptoms and it was just brushed off as IBS. So, I paid, and the specialist told my gynaecologist that I really needed a scan, which then diagnosed the endometriosis on my bowel. So, the specialist put me on his NHS list – I looked into doing the next part privately, but it was too expensive. The specialist has suggested I'd need surgery, but the waiting list is 6 and half years long."

Participant K is adamant that whilst Covid-19 has had a big impact on some recent communications and waiting times, there are deeper rooted issues around poor NHS support for people with endometriosis.

"When I spoke to the practice manager about pain management it didn't go down well. They don't understand. The practice manager said, "my friend has endometriosis and they've had a hysterectomy" and I explained that this procedure isn't a cure, just because you know someone else is OK with it, people manage pain and health issues in different ways. They just said that they were doing everything they can for me. I was understanding but I said maybe they could give me a little bit more support. I've asked the support for my mental health and again, their answer is just tablets."

I'm on quite a lot of strong painkillers at the moment, so I take Tramadol, Oramorph, and Co-codamol when needed. It's not the best option for me because I have a 4-year-old daughter to look after.

I understand that medical staff's hands are tied because there is no cure but in terms of support, I don't really get a lot, and it's been quite difficult."

Conclusions:

"In England they have a women's physiotherapist. it'd be great if there was one of these in Wales. I've never been offered that type of support."

If it wasn't for the endometriosis nurse in Cardiff that you can self-refer to, I wouldn't have had this appointment next week so soon.

It's people like them [endometriosis nurse] that are a middle ground for patients like me so I can speak to them when I need to, and they can help me out and tell me what to say to the doctors or give me advice on what to do next. It's definitely a massive help. We've got someone that understands our condition directly.

I think the GPs need a better understanding of the condition because they're always the first point of contact for anything. and I think if they did, they wouldn't be so dismissive.

I try my best and I feel so lucky to have such a supportive partner and family who really do understand. But I still feel a lot of guilt, I often wonder if I could be a better parent for her because I can't go to the park with her. I can't take her out on walks and things because I'm in so much pain majority of the time. I just feel that she misses out on things that she shouldn't be missing out on."

Participant L

Age: 72

Sex: Female

Health Board: Betsi Cadwaladr University Health Board.

Key themes:

- Covid-19 causing communication issues and extending waiting times
- Having to access private treatment
- Positive third sector support
- Lack of support from NHS

Background:

Participant L suffers from solitary sclerosis, a rare and progressive condition that can cause an individual to develop progressive motor impairment which is attributable to a single lesion.

Whilst she described her symptoms as 'not being desperately bad at all' she explained how she had developed a limp and has issues with her balance.

Prior to the pandemic the participant took part in a month-long clinical trial for fampridine – a drug used to improve walking speeds for individuals diagnosed with multiple sclerosis and solitary sclerosis. Fampridine was initially brought to her attention through the MS Society, an organisation she engages with regularly. She subsequently spoke to her consultant, based in Chester, who explained that it was not approved by the NHS in England, but was approved in Wales. A referral was made to Glan Clwyd Hospital, and she subsequently participated in a clinical trial.

She explained that having been part of the trial, she felt, along with her consultant and her husband, that there was a marked improvement in her walking ability and speed. As such, her consultant considered that she would benefit from taking fampridine. However, due to the length of time it was taking for her to be prescribed the medication, which she attributed to delays caused by the pandemic, she decided to pay privately for the medication. She has been in touch with her MP and her MS about these issues, and described the process of getting the medication as *"awfully long."*

Conclusions:

Participant L explained that whilst she concedes that her condition is progressive in nature, she does feel as though her health would be better if the pandemic had not happened and she was able to have had earlier access to fampridine. She explained that the process of trying to get the medication has caused her to feel anxious *"all the time"* and that her confidence has been affected.

The participant explained that it has been an extremely long process in order to be prescribed fampridine and said that she sometimes feels that the pandemic is being used as an excuse for the delays. She also expressed some frustration that she only found out about fampridine from members of her MS Society group, and it had not been raised with her by her consultant.

Participant M

Age: 38

Sex: Female

Health Board: Cardiff and Vale University Health Board.

Key themes:

- Lack of mental health support
- Lack of knowledge of condition in the NHS
- Poor support from NHS and referrals regularly refused
- Issues around cross health board treatment
- Breaches of NICE (National Institute for Health and Care Excellence) guidance
- Positive support from third sector

Background:

Participant M has had a long and complex history with endometriosis which has a big impact on her adult life. During her interview she highlights the lack of support she has had from the NHS during the entire period.

"My medical history for endometriosis is complex. My diagnosis came 23 years after my symptoms started. I have absolutely no doubt that had I been diagnosed properly the first time I wouldn't have other health conditions

I've been suicidal before, due to my illness and due to endometriosis. I don't want to go down that route again. This is one of the reasons I have gone privately. I felt penalized for going private. When I asked the general gynaecologist if I could have a referral to the endometriosis nurse who's in our health board was told "no" because if I go private, I'm not allowed to have any access to NHS help."

Participant M is clear that both internal and external communications have been a huge problem for her and led to key decisions and appointments taking longer to happen.

"I need to see a specialist which I think is quite difficult. I saw a rheumatologist in September (2021) about my pain. She wrote a letter to my GP. When I contacted my GP, probably a month ago, to ask what was happening, they hadn't received a letter. I was surprised, I had received a letter, but they said "we've had nothing here. The letter hasn't arrived."

It is such bullshit! I got sent the letter! I had the letter in my hand! I've learned from my 23 years of hell to ask to be copied into every correspondence.

This happens all the time whatever doctor surgery it is. My specialist jokes that it's "the NHS shredding service"

Participant M is clear that Covid-19 has had a big bearing on waiting times over the last few years. This in turn has led to extremely frustrating experiences with refused referrals another key issue.

"Waiting times feel like they have been compounded since the pandemic. Being a disabled person during the pandemic has been very difficult, and the media bombard me with the message that I don't matter. If I died of Covid tomorrow, I'd be labelled as someone with underlying health conditions"

Participant M also states how important the support of Fair Treatment for the Women of Wales (FTWW) has been during this period, not only for herself but for its 1,500 members who she communicates with regularly. She recalls that after a particularly challenging NHS appointment how the group's support and advice helped her in that difficult period.

"It's a place to be proactive and find out where to access different support. I've always said that FTWW saved my life, and I am not exaggerating that. I found them when I came out of my final NHS appointment before I got diagnosed with endo. After a very brutal internal examination by a male consultant who I still don't think should have done so because he was incredibly rude to me.

The first thing I did say when I could speak was say "I've had enough. I'm going to kill myself" and my partner pulled me through that. To this day I am surprised that I was allowed to walk out of there in that state. There was no real attempt to actually comfort me or to say "what do you want us to do? How can we make this better?" The attitude was that I was completely wasting their time."

Conclusions:

"In England you have the power of choice. You can ask to be referred to a specialist that is good at certain types of diagnosis even if they are miles away. But in Wales the block funding system means health boards have to refer you and use a 'transfer' system to ensure health boards aren't 'out of pocket' for taking on too any patients outside of their area. This means you live in a postcode lottery because you can be refused a referral due to lack of funding.

I have questioned my own sanity at times. I ask myself am I really that bad. The diagnostic delay is so long in Wales, the longest wait of all the home nations, where you could be waiting an average of nine years.

I was not offered mental health support until I got diagnosed with ME. And then the only reason I was offered it was because it was part of the NICE guidelines at the time.

I am incredibly critical of my experiences of the NHS. I've been in the media talking about it. But the reason I do it is because I love the NHS and I want it to be better funded. I want it to thrive. I want it to offer the services that patients actually need."

Focus groups

Focus Group 1

Number of participants: 12

Theme: Endometriosis and Adenomyosis

Focus Group 2

Number of participants: 10

Theme: Women's Health waiting times

Summary:

Two focus groups were facilitated on 5 and 6 of January in partnership with Fair Treatment for the Women of Wales (FTWW). Discussions focused on issues impacting women's health in Wales. Rhun ap Iorwerth MS attended the focus group on 5 January and Mike Hedges MS attended the focus group on 6 January.

Key Themes:

- **Early advice and initial diagnosis of Endometriosis very poor**

Several participants commented on the poor early advice given by GPs, which had led to their condition not being properly diagnosed.

"Early advice, as in other cases were very poor. I was pushed on the pill, which actually just masked my endometriosis. Pain during smear tests is what pushed me to get diagnosed properly. 2016 was the first time a health professional asked me about the pain"

"Every time I move health board I have to prove myself every single time, it's exhausting. The Head of Gynaecology told me, 'I don't believe in Endo, there is no need for them to have surgery space'. I was told last week that there is 7.5 years of backlog which is horrific"

"Endometriosis is not a rare health condition, it has a 1 in ten ratio like diabetes. There are few specialists and a system that doesn't let us access them, it's nothing short of a disgrace"

- **Very long waiting times**

All participants noted that waiting times for women's health services are worse than they have been in a long time, with the added frustration of finding it very difficult to find out how long they actually are, with many only discovering the true details from support groups online.

"My follow up appointment with my current gynaecologist has needed to be pushed back due to the sheer amount of people waiting to be seen on an urgent basis"

"Waiting lists were up the creek before Covid – now hearing they are 5, 6, 7 years"

"Waiting lists to pandemic was huge. Now there is just no explanation – you have to constantly advocate for yourself; it's exhausting to bang your head on a brick wall"

"I was on a waiting list for a follow up neurology appointment. Had a letter that said due to length of time since I was last seen, was told I couldn't have another appointment. Luckily I know the system and rang the right people to explain I was still bleeding and needed treatment. I was eventually out back on the waiting list, and there was at least a 12 months appointment. They can't take people off a waiting list just because they have been waiting a long time!"

- **Women not being listened to or taken seriously leading to condition not being treated in a timely manner**

A constant theme across both focus groups was participants noting that women were not being taken seriously when approaching the NHS. Participants commented on the frustration when dealing with the NHS, with several mentioning an apparent 'gender bias'.

"I was told that it's all in your head, 'there is nothing wrong with you' – at 17 I went privately and was diagnosed with Stage 4"

"I think there is a gender pain bias there as well – my husband got support to manage pain straight away, I was batted away and told to take paracetamol"

"My GP said it was all in my head"

"Women are not being listened to...I can walk in and list my symptoms and get totally ignored"

"I believe the more common poignant theme is the simple issue of women not being listened to, and therefore not being able to access appropriate healthcare to treat their conditions in a timely fashion"

- **Referrals between health boards and across border extremely poor**

Many participants were critical of the referral system in Wales, with several commenting on the barriers that they had faced.

"There seems to be a culture in Wales of not referring people to specialists out of areas but people want to be treated by a specialist, this reluctance in Wales to refer to other"

health boards or over the border is poor, there is no respect for the people that make referrals and they just get disregarded."

"Out of Health board cases get sent back all the time, the communication is a mess. I run a group and the stories are consistent, Swansea Bay Health Board comms is awful, nothing is being done. The situation was dire before this but now...I am worried about everyone who has to deal with this medical trauma"

"I was not doing well, and I know in Bristol that they were getting people in the same day. There was a lack of joined up services but all the health board said was 'we haven't had a meeting about that yet'. We need a women's service that deals with the issues that women face."

- **Lack of support from NHS in key areas such as mental health**

A theme that kept appearing was the lack of support given by the NHS to participants' mental health. Many commented on the overwhelming mental toll their experiences had on them.

"I am 28, my ovaries, womb, bowel out, this disease has taken everything and I had no support from the NHS. No Mental health support, physio, pelvic flooring...I could go on and on"

"I went to commit suicide due to endo, I lost my job, nearly lost my family – it's such a painful condition it has to be shared"

"There is inequality of access in Wales and a clear lack of Mental Health Support – experiences will have huge strain mentally as well as physically"

- **Third sector providing essential support that is currently not happening within the NHS.**

Whilst participants were critical of the support they received from the NHS, they were keen to emphasise the positive experiences they had with third sector organisations, with several participants noting that they filled a gap the NHS weren't providing.

"FTWW and Endometriosis UK forums keep you sane – it feels they are doing the job of the NHS when it comes to providing support"

"Support again was poor, Powys women have to go over the border and are being let down. You have to be an expert yourself, if it wasn't for support of FTWW then I don't know what I would do and I dread to think where some of us might be."

- **Many participants having to seek private treatment**

Several of the participants noted that, due to the issues they faced with getting support from the NHS, they felt that they were left with no option other than to seek private treatment, which often caused them additional financial burdens.

"In the end with help from my dad I had to pay 10.5k for a private surgery, if it would have been left then god knows what would happen, my large bowel could have perforated and could have killed me. Delays of months and years, I am beyond frustrated for the system, I had to pay money for a hospital in England. It worries me what the state of the NHS will be with endometriosis in Wales, we are behind as it is now, where will we be?"

"I took out a personal loan for private surgery and stage 4 endometriosis was found. I was left a bit high and dry then as I couldn't afford further treatment. We are still paying off the loan now and due to misdiagnosis initially we are actually looking at negligence."

"I had a breast cancer scare that ended in me going private. After initial diagnosis I rang them back after 2 weeks, unfortunately I was told there was a backlog of 4 weeks due to Covid, after 4 weeks I rang back and was told now 6-8 weeks...this was untenable. It wore down my mind and mental health, 2 weeks is long enough with a cancer scare, especially as the prognosis gets worse and worse. I eventually spoke to a manager who said it was now 12 weeks, the time just kept increasing. My husband put his foot down and said we were going private"

- **Lack of knowledge around women's health in NHS**

Many of the participants felt that there was real lack of knowledge of women's health issues within the NHS in Wales.

"I know more about my condition than my GP or any gynaecologist I've seen in Wales. I'm made to feel like a drug seeker when requesting more pain relief, or even when I say its not touching the sides. How many people that are passing out and vomiting in pain actually want the drugs? We don't. We want a normal life, we'd rather be without pain, so why make us feel like crap for asking for it?"

"I would sum up my experience, that consulting with any medical professional I have felt like the most knowledgeable person in the room about my condition. There are no specialists in Wales who oversee my care"

- **Lack of specialists in Wales**

Participants frequently mentioned the importance of being seen by a specialist at the right time, and the frustrations of not being given that option when speaking to a GP.

"I have been referred for 20 years, but didn't know a specialist even existed since I spoke to other people, no mention of this from NHS over the years and I just assumed I was under the best care.

"Every time I move health board I have to prove myself every single time. I went from Swansea Vale Health Board and The Doctor told me there was nothing else he could do to me , he wouldn't refer me to another health board. I had to fight and fight in the end to be seen in Cardiff by a specialists. Being seen by a specialist at the right time is crucial and there just aren't enough in Wales"

There is a real lack of awareness around specialities...it's quite telling that my GP was at a loss where to refer me due to a lack of specialism, I feel for people that just can't afford private care. There needs to be an overhaul of the system, if England has centre of excellencies, why in Wales are we being denied that support. You are left feeling you are not worthy of care, left all alone and your entire life is affected"

- **Communication getting worse during Covid-19**

Several participants noted that communication during Covid-19 had been extremely poor. However there was a constant message that communication pre-pandemic was also disappointing.

"Appointments have fallen off the radar due to Covid, I was waiting on a dermatologist, haven't heard for them over two years. I run a support group of 60 people in the same boat, no one has heard anything – they are like the dying of the dinosaurs – they have gone extinct recently. If you are diagnosed with a rare auto immune rheumatic disease in Wales it's an impossible situation, there is a complete lack of recognition that these illnesses are serious enough to warrant specialist care."

"The staff work very hard and it is hard to be critical during a pandemic, but the majority of my healthcare has been poor prior to the pandemic. Communication between Consultants and with patients and GP lets the system down at every turn"

Agenda Item 10

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

Document is Restricted

SUPPLEMENTARY LEGISLATIVE CONSENT MEMORANDUM (MEMORANDUM NO 2)

HEALTH AND CARE BILL

1. This legislative consent memorandum is laid under Standing Order (“SO”)

29.2. SO29 prescribes that a legislative consent memorandum must be laid, and a legislative consent motion may be tabled, before Senedd Cymru if a UK Parliamentary Bill makes provision in relation to Wales for any purpose within, or which modifies, the legislative competence of the Senedd.

2. The Health and Care Bill (“the Bill”) was introduced in the House of Commons on 6 July 2021. On 18 November the UK Government tabled 54 amendments for consideration at Commons Report Stage and 24 of these amendments make provision which falls within the legislative competence of the Senedd. All of these amendments were agreed on 23 November and form part of the Bill which commenced consideration by the House of Lords on 24 November. The Bill as amended can be found at: <https://bills.parliament.uk/publications/44008/documents/1051>

3. It was not possible to lay this Memorandum within the normal two weeks prescribed in SO29, owing to the complexity of the amendments tabled and the on-going discussions with the UK Government on outstanding issues which I had hoped would be resolved and positively covered in this Memorandum. This Memorandum has been laid as soon as possible after the tabling of these amendments allowing for analysis of their effect. However, there remain some outstanding issues which are still the subject of on-going discussions with UK Government.

Policy Objective(s)

4. The UK Government’s stated objective is to enact policies set out in the NHS’s recommendations for legislative reform, following the NHS Long Term Plan, and the White Paper, Integration and Innovation: working together to improve health and social care for all. The UK Government says that the Bill builds on the NHS’s own proposals for reform, aiming to make it less bureaucratic, more accountable, and more integrated, and to incorporate lessons learnt from the pandemic.

Summary of the Bill

5. The Bill is sponsored by the Department of Health and Social Care.

6. The key provisions of the Bill cover a number of areas, set out briefly below.

a) Addressing of concerns raised by NHS England, such as establishing existing Integrated Care Systems (ICSs) on a statutory footing, formally merging NHS England and NHS Improvement, and making changes to procurement and competition rules relating to health services. The Bill also includes proposals to give the Secretary of State for Health and Social Care powers to direct NHS England and to decide how some other health services are organised. It gives the Secretary of State powers to transfer functions between some of the ‘Arm’s Length Bodies’ that lead, support and regulate healthcare services in England and to delegate other functions of the Secretary of State to those bodies both in relation to the health service in England, and to intervene in proposed changes to the way health services are delivered.

b) The Bill does not cover wider reforms of the social care and public health systems, although it does provide for some changes in these areas; ICSs are intended to improve coordination between the NHS and local authority services. For social care, the Bill provides for the Care Quality Commission (CQC) to assess how local authorities in England deliver their adult social care functions

and it aims to improve data sharing. There are also measures to streamline how people with ongoing care needs are discharged from hospitals.

c) Public health measures in the Bill relate to food advertising, food information for consumers and water fluoridation.

d) The Bill also addresses safety investigations and establishes the Health Services Safety Investigations Body as a statutory body, and makes changes to the system of medical examiners.

e) Other matters covered by the Bill include the regulation of health and care professionals, the collection and sharing of data (including measures to support the development of new medicine registries), international healthcare, and hospital food standards.

Update on position since the publication of the first Legislative Consent Memorandum

7. The Welsh Government laid a Legislative Consent Memorandum in respect of the Bill on 1 September, based on the Bill as introduced to Parliament on 6 July.

8. The Memorandum stated that, as a number of the Bill clauses were of concern to the Welsh Government, despite the merits of some of the clauses, the Welsh Ministers' final position on being able to recommend consent would be subject to the outcome of ongoing discussions with the UK Government regarding amendments to the Bill.

9. Since the publication of the first Memorandum, we have secured amendments from the UK Government which address the majority of our concerns.

10. The UK Government has also amended the Bill in other areas at our request, in order to change existing Bill provisions on behalf of Wales or extend new provisions to Wales. These are set out at paragraphs 36-54 below.

11. These amendments were agreed at House of Commons Report Stage on 23 November 2021.

12. The Senedd will wish to note:

Clauses 88-94 (formerly Clauses 86-92): Arm's Length Bodies Transfer of Functions

13. Constructive discussions between Welsh Government and the Department of Health and Social Care led to the UK Government agreeing amendments which addressed all my areas of concern and which I was fully supportive of. However, an amendment to this provision was not tabled for consideration at Commons Report Stage along with the other amendments tabled, as whilst some aspects of the amendment were agreed by the UK Government and all three Devolved Governments, the UK Government was unable to secure agreement from all the Devolved Governments to further proposed amendments to the provisions.

14. Discussions with the Department for Health and Social Care on this matter are continuing to seek to ensure that an acceptable position for Wales is reached.

15. Until these discussions are resolved I am unable to support these clauses being included in the Bill.

Clauses 149, 144 and 91 (formerly clauses 89, 125 and 130): Consequential Amendments to Senedd Legislation

16. As set out in the first Legislative Consent Memorandum, these clauses provide the Secretary of State with the powers to, by regulation, make provision which is consequential on the Bill. This includes provision that amends, repeals, revokes or otherwise modifies provision made by, or under, an Act or Measure of the Senedd.

17. I and my officials have met with Minister Argar and his officials on a number of occasions to discuss these provisions. The UK Government are of the view that these are standard clauses and that we similarly take powers in Senedd Acts to make consequential amendments to UK Government legislation.

18. UK Government officials have provided examples of how these powers may be used – the amendments likely would be of a minor nature, for example the changing of the name of an English organisation which is referred to in Senedd legislation where a transfer of functions has occurred and Minister Argar has also given a written commitment to making a

Despatch Box statement in relation to Clause 149, the main provision of concern in this regard, on how these powers might be used.

19. Minister Argar has yet to make the Dispatch Box statement.

20. Once that statement has been made I will determine whether, in the light of all the assurances given by the UK Government, the risk presented by the provisions is acceptable.

Changes to the Bill since the publication of the first Legislative Consent Memorandum for which consent is required

21. The following clauses, which make provision in relation to Wales and are within the legislative competence of the Senedd, have been amended by the UK Government during House of Commons Report Stage:

Clause 87 (formerly Clause 85): Medicines information systems

22. In relation to inappropriate use of data, amendment 116 limits the scope of the purposes for which medicine information systems regulations can be made under clause 87. The amendment provides that provision in the regulations for a purpose in relation to clinical decision making can only be made where there is a connection with the safety of such decisions relating to human medicines.

23. The concerns of the Welsh Government regarding the availability of data to Welsh Ministers for purposes within devolved competence such as clinical decision making, and further concerns regarding the overlap of data collection for the purposes of the Registry with existing data gathering in Wales have been addressed by amendment 118, as well as the commitment to consult on provisions made in regulations made under the provisions. Amendment 118 requires that secondary legislation made under it must provide for information to be collected by the Welsh Ministers or a person designated by them such as Digital Health and Care Wales (DHCW), subject to specified exceptions in that secondary legislation. The amendment ensures where appropriate, data remains available for use by Welsh Ministers.

24. Finally, in addition to the safeguards agreed on the face of the Bill as introduced, amendments 117 and 121 require that the Welsh Ministers be consulted on any regulations or directions relating to medicine information systems which relate to Wales.

25. Taken together I am content that the amendments made to these provisions address the key concerns of Welsh Government and consequently I can now support this Bill clause.

Clause 136 (formerly Clause 120): International healthcare arrangements

26. We had two concerns regarding this clause as introduced.

27. Firstly the provision to allow the Secretary of State to confer functions on and/or delegate functions to Welsh Ministers and public authorities in Wales, when making regulations to make provision for the purpose of giving effect to healthcare agreements.

28. To resolve this, Amendment 124 amends the definition of a “relevant public authority” to which the Secretary of State can confer or delegate functions to when making regulations about international healthcare agreements under the Healthcare (European Economic Area and Switzerland Arrangements) Act 2019 (“HEEASA”), by excluding both the Welsh Ministers and other devolved Welsh authorities from that definition. Amendments 122 and 123 bring Welsh Local Health Boards into the scope of the Secretary of State’s regulation making power to ensure that existing functions already conferred on them regarding planned healthcare applications remain.

29. Our second concern was the proposal to only consult with the Welsh Ministers on draft regulations giving effect to international healthcare agreements, meaning that should the Welsh Government have concerns regarding unreasonable or unfunded pressures on the NHS in Wales arising from such agreements, those concerns may not always be taken into account.

30. Amendment 125 will amend HEEASA to confer a power on the Welsh Ministers enabling them to make regulations in devolved areas for the purpose of giving effect to international healthcare agreements, which includes the power to delegate functions to, and/or confer functions on, all devolved Welsh authorities. The regulations will be subject to the negative procedure. Should the Welsh Ministers fail to exercise this power to confer relevant functions onto the Local Health Boards regarding healthcare agreements, the Secretary of State may confer those functions, as set out in the previous paragraph. I am of the view that this amendment addresses Welsh Government concerns about the Secretary of State for Health legislating in relation to devolved areas.

31. I am mindful of the fact that the ability of the Welsh Ministers to have the power to place reciprocal healthcare function on Local Health Boards and other devolved Welsh authorities in Wales does not remove the ability for the UK Government to enter into reciprocal healthcare agreements that could lead to additional pressures on the Welsh NHS. However I am of the view that the amendments are a significant shift from the position of the Bill as introduced and together with the Memorandum of Understanding on the engagement of the Devolved Administrations in the development of new and revised reciprocal healthcare agreements – which I will forward to the Committee in due course - provide sufficient protection of the devolution settlement.

32. Consequently I can now support this Bill clause.

Clause 142 (formerly Clause 123): Regulation of health care and associated professions

33. While the regulation of health professionals is reserved, the regulation of persons who are not professionals but who are groups of workers concerned with the physical or mental health of

individuals falls within devolved competence. The clause as introduced in the Bill would have extended the power of the Secretary of State to regulate these additional groups of workers.

34. Amendment 127 requires the consent of the Welsh Ministers to an Order in Council made under section 60 of the Health Act 1999 that is within the legislative competence of the Senedd and brings into regulation a group of workers who are not professionals, but who are concerned with the physical or mental health of individuals.

35. I am content that this amendment address the concerns of Welsh Government in respect of this provision and consequently I can now support this Bill clause.

Clause 143: Medical Examiners

36. Amendment 128 amends Clause 143 of the Bill to insert a new section 18B into the Coroners and Justice Act 2009 in England and Wales, which sets out a power for Welsh NHS bodies to appoint medical examiners. A duty will also be imposed on the Welsh Ministers to ensure that enough medical examiners are appointed in the healthcare system in Wales, that enough funds and resources are made available to medical examiners to enable them to carry out their functions of scrutiny to identify and deter poor practice, and to ensure that their performance is monitored.

37. This amendment has been made at our request to enable appointment of medical examiners by a range of Welsh NHS bodies rather than only Local Health Boards in Wales (as is set out in the current provision of the 2009 Act). This will enable more collaborative working across Welsh NHS bodies to ensure the effective delivery of the medical examiners scheme and bring provisions broadly in line the position in England.

38. While the subject matter of Part 1 of the 2009 Act, which is where this provision will be inserted, is reserved by paragraph 167 of Schedule 7A to the Government of Wales Act 2006, consent is nonetheless required because the amendment imposes a reserved function on Welsh NHS bodies and places duties on Welsh Ministers.

39. I support this amendment as it has been made at our request.

Clauses 122-125: Virginitly Testing

40. Virginitly testing is the examination of female genitalia for the purpose, or purported purpose, of determining virginitly.

41. The World Health Organisation and the Royal College of Obstetricians and Gynaecologists position is that virginitly tests have no scientific merit or clinical indication, as it is not possible to tell whether a woman has had intercourse through this type of examination. The procedure is not carried out on the NHS as it is not recognised as a medical procedure. Virginitly testing seems to predominantly take place in private healthcare settings and to be carried out by healthcare professionals. However, it can also take place in other settings such as the home, where family members or community leaders may perform the test.

42. Amendments 36-39 make carrying out virginitly testing, as well as offering to carry out virginitly testing or aiding or abetting a person to carry out virginitly testing, an offence. The penalty for the offence is:

- on summary conviction, to imprisonment for a term not exceeding the maximum summary term for either-way offences or a fine (or both);
- on conviction on indictment, to imprisonment for a term not exceeding 5 years or a

fine (or both).

43. We have agreed this provision extends to Wales as to not do so would risk Wales being left behind on this important issue. Our Programme for Government commits to making Wales the safest place in Europe to be a woman and this would mean that women and girls in Wales have fewer protections than their counterparts in England.

44. The amendment falls within the legislative competence of the Senedd. The purpose underpinning the amendment is safeguarding and protecting the health and welfare of women and girls. Both safeguarding and health and welfare are within the legislative competence of the Senedd.

45. I support this amendment as it has been extended to Wales at the request of the Welsh Government.

Clause 135: Reimbursement to Community Pharmacies

46. Amendment NC62 amends section 88 of the NHS (Wales) Act 2006, creating an exemption where pharmacy contractors do not need to be reimbursed for medicinal products that are used for vaccines and immunisation or for the prevention and treatment of disease that could become a pandemic, where those products have been procured centrally.

47. Amendment 129 provides the Welsh Ministers with a regulation making power to bring into force the amendments to section 88 of the 2006 Act. Amendment 132 confers a power on the Welsh Ministers to make transitional provision in connection with the coming into force of the amendments. A statutory instrument made in the exercise of these powers is not subject to any Senedd procedure.

48. When there is a health emergency (such as the current global pandemic) the current supply and reimbursement arrangements for specific products are not fit for purpose. There is no real 'competition' in the supply chain as there is not enough product for global demand and prices rise as health organisations worldwide try to source the same product. To ensure continuity of supply protecting UK stock intended for UK patients, the government may centrally purchase some stock. In these scenarios the Welsh Government wants to have the option to be able to supply the product 'directly' to pharmacies, without needing to sell into the supply chain. Welsh Government may use the typical pharmaceutical supply chain as a logistic service provider to deliver the medicine (the Welsh Government would need to pay them for this service) but the Welsh Government would retain title of the medicine.

49. This may involve supplying to pharmacies free of charge. In these circumstances the Welsh Government does not want to have to reimburse pharmacies, otherwise the government has to pay twice for the product - once to buy it in the first place and again in reimbursing the pharmacy.

50. We do not want to sell these centrally secured medicines as if it were a manufacturer into the supply chain to sell onto pharmacies in the usual way, as this would give rise to the opportunity for wholesalers, once they own the stock, to export it or sell at a much higher price than is usually paid.

51. Amendment 129 provides the Welsh Ministers with a regulation making power to bring into force the amendments to section 88. Amendment 132 confers a power on the Welsh Ministers to make transitional provision in connection with the coming into force of the amendments. A statutory instrument made in the exercise of these powers is not subject to any Senedd procedure.

52. I have agreed these amendments in the Bill are extended to Wales because, whilst the amendment relates to Welsh legislation, officials consider it is prudent and timely to agree to the UK Government making these amendments via the Bill, given the Bill already contains several provisions relating to medicines and devolved matters, and there is a need to ensure Wales' legislation does not preclude supply without reimbursement. The powers to commence the provisions that apply in Wales enable these amendments to be commenced in line with our own timeframes.

53. These amendments fall within the legislative competence of the Senedd. Whilst medicinal products, including manufacture, authorisations for use and regulation of prices is reserved under paragraph 147 of Schedule 7A to GOWA, the purpose of the proposed amendments relates to health and remuneration for pharmaceutical services, both of which are devolved matters.

54. I support these amendments as they have been extended to Wales at our request.

Welsh Government position on the Bill as amended

55. As set out above, we have secured agreement with the UK Government regarding the majority of areas of concern. In addition the UK Government has at the request of the Welsh Government amended the Bill to reflect the situation in Wales with regard to Medical Examiners, and extended UK Government amendments regarding Virginitiy Testing and Reimbursement to Community Pharmacies to Wales. I support consent in respect of all these provisions.

56. However, the agreed amendment with regard to Arm's Length Bodies was not tabled and in addition, Minister Argar has to date not made the Dispatch Box statement with regard to powers to make consequential amendments.

57. Until the above matters are resolved, I am unable to recommend consent to all of the clauses in the Bill which relate to areas within devolved competence as it is currently constituted.

Financial implications

58. There have been continuing discussions with UK Government regarding costs, and I have received some assurances. Broadly, Minister Argar has confirmed that the Barnett Formula will apply to additional costs arising from provisions in the Bill impacting on Wales as set out in the Statement of Funding Policy.

59. In relation to reciprocal healthcare specifically, the UK Government has confirmed that it will continue to fund the costs of treatment provided overseas to Wales' residents under any new healthcare agreements.

Conclusion

60. I welcome the amendments the UK Government has made to the Bill to address the majority of the areas of concern of the Welsh Government and the further amendments made at our request to reflect the situation in Wales with regard to Medical Examiners and to extend UK Government amendments regarding Virginitiy Testing and Reimbursement to Community Pharmacies to Wales.

61. However, until the concerns regarding Arm's Length Bodies and the powers to make consequential amendments are resolved I am unable to recommend consent to all of the clauses in the Bill which relate to areas within devolved competence as it is currently drafted. I will set out more detail on the Welsh Government's position as the situation develops and further information becomes available.

62. A further Supplementary Legislative Consent Memorandum will be brought forward if required.

Eluned Morgan MS

Minister for Health and Social Services

**SUPPLEMENTARY LEGISLATIVE CONSENT MEMORANDUM
(MEMORANDUM NO 3)**

HEALTH AND CARE BILL

1. This legislative consent memorandum is laid under Standing Order (“SO”) 29.2. SO29 prescribes that a legislative consent memorandum must be laid, and a legislative consent motion may be tabled, before Senedd Cymru if a UK Parliamentary Bill makes provision in relation to Wales for any purpose within, or which modifies, the legislative competence of the Senedd.
2. The Health and Care Bill (“the Bill”) was introduced in the House of Commons on 6 July 2021. The Bill has concluded its passage through the House of Commons. Consideration of the Bill in the House of Lords commenced on 24 November, with Lords Committee stage beginning on 11 January 2022. The Bill as introduced to the Lords can be found at: <https://bills.parliament.uk/publications/44008/documents/1051>
3. On 24 January, the UK Government tabled a set of amendments in relation to Arm’s Length Bodies Transfer of Functions, Hymenoplasty and Mandatory Reporting as set out below which make provision falling within the legislative competence of the Senedd.

Policy Objective(s)

4. The UK Government’s stated objective is to enact policies set out in the NHS’s recommendations for legislative reform, following the NHS Long Term Plan, and the White Paper, Integration and Innovation: working together to improve health and social care for all. The UK Government says that the Bill builds on the NHS’s own proposals for reform, aiming to make it less bureaucratic, more accountable, and more integrated, and to incorporate lessons learnt from the pandemic.

Summary of the Bill

5. The Bill is sponsored by the Department of Health and Social Care.
6. The key provisions of the Bill cover a number of areas, set out briefly below.
 - a) Addressing of concerns raised by NHS England, such as establishing existing Integrated Care Systems (ICSs) on a statutory footing, formally merging NHS England and NHS Improvement, and making changes to procurement and competition rules relating to health services. The Bill also includes proposals to give the Secretary of State for Health and Social Care powers to direct NHS England and to decide how some other health services are organised. It gives the Secretary of State powers to transfer functions between some of the ‘Arm’s Length

Bodies' that lead, support and regulate healthcare services in England and to delegate other functions of the Secretary of State to those bodies both in relation to the health service in England, and to intervene in proposed changes to the way health services are delivered.

- b) The Bill does not cover wider reforms of the social care and public health systems, although it does provide for some changes in these areas; ICSs are intended to improve coordination between the NHS and local authority services. For social care, the Bill provides for the Care Quality Commission (CQC) to assess how local authorities in England deliver their adult social care functions and it aims to improve data sharing. There are also measures to streamline how people with ongoing care needs are discharged from hospitals.
- c) Public health measures in the Bill relate to food advertising, food information for consumers and water fluoridation.
- d) The Bill also addresses safety investigations and establishes the Health Services Safety Investigations Body as a statutory body, and makes changes to the system of medical examiners.
- e) Other matters covered by the Bill include the regulation of health and care professionals, the collection and sharing of data (including measures to support the development of new medicine registries), international healthcare, hospital food standards and, included through amendment, creating an offence of virginity testing.

Update on position since the publication of the second Legislative Consent Memorandum

- 7. I laid a second Legislative Consent Memorandum ("Memorandum No. 2") on 17 December 2021, following the tabling by UK Government on 18 November of 54 amendments, 24 of which made provision falling within the legislative competence of the Senedd. On 23 November the 24 UK Government amendments were agreed at Commons Report stage and now form part the Bill as introduced to the House of Lords.
- 8. Memorandum No. 2 outlined the areas of agreement reached between the Welsh Government and UK Government as a result of the introduction of negotiated amendments to the Bill agreed by the House of Commons.
- 9. It also provided an update on areas where we were still in disagreement with UK Government, the areas being Clauses 88-94: Arm's Length Bodies Transfer of Functions and Clauses 149, 144 and 91: Consequential Amendments to Senedd Legislation.
- 10. Since the publication of Memorandum No. 2, we have secured amendments from the UK Government which address our remaining concerns regarding Clauses 88-94: Arm's Length Bodies Transfer of

Functions, and have reached an agreed position with UK Government regarding Clauses 149, 144 and 91: Consequential Amendments to Senedd Legislation.

11. The UK Government has also tabled amendments including new clauses to the Bill in other areas and, at our request, extended the new provisions to Wales. The areas are the Criminalisation of Hymenoplasty and Mandatory Reporting. These are set out at paragraphs 38-50 below.

12. These amendments were tabled at House of Lords Committee Stage on 24 January 2022.

13. The Senedd will wish to note:

Memoranda of Understanding underpinning Clauses requiring the Secretary of State to Consult with the Welsh Ministers

14. There are three areas of the Bill where currently the UK Government is required to consult with the Welsh Ministers before making Regulations. These are:

- Clause 87: Medicines Information Systems
- Clauses 88-94: Arm's Length Bodies Transfer of Functions
- Clause 136: International healthcare arrangements

15. The Memorandum of Understanding concerning Medicines Information Systems is yet to be drafted by UK Government. We have communicated to UK Government the need to develop this Memorandum as soon as possible with a view to it being in place before the provisions come into force.

16. The Memorandum of Understanding concerning Arm's Length Bodies will no longer be required if the tabled amendment¹ as set out below in paragraphs 20 to 23 is agreed.

17. The Memorandum of Understanding concerning International Healthcare Agreements is at an advanced stage of agreement and it is our intention that a final draft can be provided to the Senedd Committees in relation to their consideration of the legislative consent memoranda on the Bill.

Changes to the Bill since the publication of the second Legislative Consent Memorandum for which consent is required

18. The following new clauses and amendments, which make provision in relation to Wales and are within the legislative competence of the Senedd, were tabled by the UK Government at House of Lords Committee stage on 24 January.

¹ Amendment 231C*

Clauses 88-94 (formerly Clauses 86-92): Arm's Length Bodies Transfer of Functions

19. The Welsh Government had three concerns regarding these clauses as introduced:
20. Firstly the provision to allow the Secretary of State to, without the consent of the Welsh Ministers, to make regulations which transfer functions between relevant bodies or provide for the exercise of functions of the Secretary of State by a relevant body, which make provision which would be within the legislative competence of the Senedd or which modify functions which are exercisable by the Welsh Ministers.
21. The bodies covered by the Bill provisions that could be impacted in this regard are the Health Research Authority, the Human Tissue Authority and the parts of NHS Digital that relate to Medical Information Systems/Medical Devices Information Systems (MDIS) and are within devolved competence.
22. To resolve this, the UK Government has now tabled an amendment² providing for a statutory consent requirement, whereby the consent of the Welsh Ministers is needed before the Secretary of State can make regulations under clauses 89 (Power to transfer functions between bodies) or 90 (Power to provide for exercise of functions of Secretary of State) where those regulations contain provision which would be within the legislative competence of the Senedd if contained in an Act of Senedd Cymru (and is not merely incidental to, or consequential on, provision which would be outside that legislative competence) or which modifies the functions of the Welsh Ministers (i.e. modifies their executive competence).
23. As the amendment, if passed, requires the Secretary of State to obtain the consent of the Welsh Ministers before making relevant regulations under section 89 or 90 rather than to consult (as on the face of the Bill), a Memorandum of Understanding underpinning the consultation process will no longer be required.
24. Secondly, our concern was the ability for the Secretary of State to transfer property, rights and other liabilities from Arm's Length Bodies to the Welsh Ministers, Welsh NHS Trusts and Wales-only Special Health Authorities in Clause 92.
25. To resolve this, the UK Government has now tabled amendments³ removing the Welsh Ministers, Welsh NHS Trusts and Welsh Special Health Authorities from the list of "appropriate persons" in the clause, thus fully addressing the concerns of the Welsh Government in this area.
26. Thirdly, Clause 91, which provides the Secretary of State with the powers to, by regulations, make provision which is consequential on clauses 88 or

² Amendment 231C*

³ Amendment 227A*; Amendment 231A*; Amendment 231B*

90 of the Bill. This includes provision that amends, repeals, revokes or otherwise modifies provision made by, or under, an Act or Measure of the Senedd.

27. This has now been addressed by the UK Government as set out in paragraphs 29 to 37 below.

28. As our concerns with regard to Clauses 88 to 94 have now been addressed I am now content to support inclusion these clauses in the Bill.

***Clauses 149, 144 and 91 (formerly clauses 89, 125 and 130):
Consequential Amendments to Senedd Legislation***

29. As set out in the first Legislative Consent Memorandum I laid on 1 September 2021, these clauses provide the Secretary of State with the powers to, by regulations, make provision which is consequential on the Bill. This includes provision that amends, repeals, revokes or otherwise modifies provision made by, or under, an Act or Measure of the Senedd.

30. I and my officials have met with Edward Argar MP, Minister of State for Health and his officials on a number of occasions to discuss these provisions. The UK Government are of the view that these are standard clauses and that we similarly take powers in Senedd Acts to make consequential amendments to UK Government legislation.

31. UK Government officials have provided examples of how these powers may be used – the amendments likely would be of a minor nature, for example the changing of the name of an English organisation which is referred to in Senedd legislation where a transfer of functions has occurred - and Minister Argar has also given a written commitment to making a Dispatch Box statement in relation to Clauses 91 and 149, the main provision of concern in this regard, on how these powers might be used.

32. Clause 144 refers to Schedule 17 which amends the Communications Act 2003 to restrict the advertising of certain food and drink products in relation to the UK. The Clause and Schedule are covered in the first Legislative Consent Memorandum on the Bill. Whilst this clause also contains provisions which enable consequential change to Senedd legislation, the UK Government has not identified this as a clause which requires the legislative consent of the Senedd and therefore will not include within the wording Dispatch Box Statement.

33. However, on the basis of the assurances provided by the UK Government on the possible use of the powers, we accept the consequential amendments which might arise from Clause 144 as an acceptable and minor constitutional risk.

34. The Welsh Government has agreed the wording of the Dispatch Box statement with UK Government.

35. The UK Government has committed to making the statement prior to the Legislative Consent Motion debate in the Senedd.
36. On the basis of the statement being made, and in the light of all the assurances given by the UK Government, I regard the risk presented by the provisions to be acceptable.
37. As our concerns with regard to Clauses 149, 144 and 91 have now been addressed I am content to support the inclusion of these clauses in the Bill.

Criminalisation of Hymenoplasty

38. Hymenoplasty, also called 'hymen repair', is a surgical intervention which involves reconstructing the hymen. In most cases, the purpose of a hymenoplasty is so that a woman can bleed the next time she has intercourse, although it should be noted that a non-intact hymen is not necessarily an indication of sexual activity. Hymenoplasty is a form of Female Genital Cosmetic Surgery. This procedure is not routinely carried out by the NHS and is usually confined to private clinics.
39. The practice is opposed by bodies such as the Royal College of Obstetricians and Gynaecologists (RCOG), the British Society for Paediatric and Adolescent Gynaecology (BritSPAG), the British Society of Urogynaecology (BSUG), and the British Society for Gynaecological Endoscopy (BSGE) who have called on the UK Government to introduce a ban on both virginity testing (subject of a previous amendment of the Bill and covered in Memorandum No. 2) and hymenoplasty.
40. The tabled amendments⁴ make carrying out hymenoplasty, as well as offering to carry out hymenoplasty or aiding or abetting a person to carry out hymenoplasty, an offence. The penalty for the offence is:
- on summary conviction, to imprisonment for a term not exceeding the maximum summary term for either-way offences or a fine (or both);
 - on conviction on indictment, to imprisonment for a term not exceeding 5 years or a fine (or both).
41. We have agreed for this provision to extend to and apply in Wales as to not do so would risk Wales being left behind on this important issue. Our Programme for Government commits to making Wales the safest place in Europe to be a woman ; if these offences did not extend to Wales it would mean that women and girls in Wales have fewer protections than their counterparts in England.
42. The amendment falls within the legislative competence of the Senedd. The purpose underpinning the amendment is safeguarding and protecting the health and welfare of women and girls. Both safeguarding and health and welfare are within the legislative competence of the Senedd.

⁴ 231H*; 231J*; 231K*; 231L*; 313ZA*; 313ZB*; *; 313ZE*; 313ZJ*; 313ZK*; 313ZM*

43. I support this amendment as it has been extended to Wales at the request of the Welsh Government.

Mandatory Reporting

44. The UK Government has tabled amendments⁵ which if passed make provision for the Secretary of State to make regulations which require manufacturers or commercial suppliers of health care products, or persons connected, to publish information about payments or other benefits (whether or not of a financial nature) made by them to health care providers, or provide such information to the Secretary of State for publication.

45. The purpose of the provisions is to ensure patients can check (or be reassured) that decisions about their treatment are being taken based on what is best for them clinically, rather than on what is profitable or beneficial for their healthcare provider. Information gathered will be available to the general public with the overarching aim of improving patient trust in healthcare providers.

46. I am of the view that it is important the policy of recording information on payments or other benefits applies across the UK.

47. The amendment falls within the legislative competence of the Senedd as their purpose relates to the provision of healthcare which is devolved.

48. Following negotiations with the Devolved Governments, UK Government has agreed that the Secretary of State must seek the consent of the Welsh Ministers before making provision in Regulations which would be within the legislative competence of the Senedd.

49. Should the consent of the Welsh Ministers not be forthcoming, the amendment also provides that the Secretary of State can in regulations make different provision for different parts of the UK in this area, which could allow for arrangements to exclude Wales-based manufacturers from reporting if necessary.

50. I support this amendment as it has been extended to Wales at the request of the Welsh Government.

Welsh Government position on the Bill as amended

51. As set out above, we have reached agreement with the UK Government regarding the remaining areas of concern, namely Arm's Length Bodies Transfer of Functions and Consequential Amendments to Senedd Legislation.

⁵ 312B*; 312C*; 312D*, 313C*, 314ZB*

52. In addition the UK Government has tabled amendments to the Bill which introduce provisions regarding the Criminalisation of Hymenoplasty and Mandatory Reporting and has, at our request, extended these provisions to Wales. I recommend consent in respect of both of these provisions.

53. My position is therefore, subject to the tabled amendments being passed by the House of Lords and the Dispatch Box Statement being committed to, I will be able to recommend the consent of the Senedd be given to all of the clauses in the Bill which relate to areas within devolved competence.

Financial implications

54. These are set out in the Memorandum No. 2.

Conclusion

55. I welcome the amendments the UK Government has made to the Bill to address the remaining areas of concern of the Welsh Government and the further amendments regarding the introduction of Criminalisation of Hymenoplasty and Mandatory Reporting provisions which, at our request, are to extend to Wales.

56. Subject to the tabled amendments being passed by the House of Lords and the making of the agreed Dispatch Box Statement, I am able to recommend consent to all of the clauses in the Bill which relate to areas within devolved competence as it is currently constituted.

Eluned Morgan MS
Minister for Health and Social Services
28 January 2022

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