# Agenda – Health and Social Care Committee

Meeting Venue:
**Hybrid – Committee room 4 Tŷ Hywel and video conference via Zoom**
Meeting date: 14 March 2024
Meeting time: 09.30

For further information contact:
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## Private pre-meeting (09.00-09.30)

(09:00-09:30)

## 1 Introductions, apologies, substitutions, and declarations of interest

(09.30)

## 2 Supporting people with chronic conditions: evidence session with ADSS Cymru and BASW Cymru

(09.30-10.30) (Pages 1 – 27)

Jacqueline Davies, Vice Chair – AWASH (All-Wales Adult Service Heads Group) and Head of Adult Social Care, Bridgend County Borough Council – ADSS Cymru

Fon Roberts, AWHoCS Member (All Wales Heads of Children's Services Group) and Director of Social Services, Isle of Anglesey County Council – ADSS Cymru

Sarah Jane Waters, BASW Cymru Member

Research brief

Paper 1 – ADSS Cymru

## Break (10.30 – 10.40)

## 3 Supporting people with chronic conditions: evidence session with the British Geriatrics Society, Diabetes UK Cymru and the Royal College of Paediatrics and Child Health

(10.40-11.40) (Pages 28 - 54)

Dr Nicky Leopold, Consultant Geriatrician - Swansea Bay University Health Board and Vice Chair of British Geriatrics Society Wales Council

Mathew Norman, Deputy Director Wales - Diabetes UK Cymru

Dr Nick Wilkinson, Royal College of Paediatrics and Child Health (RCPCH) Wales Officer

Paper 2 - British Geriatrics Society

Paper 3 - Diabetes UK Cymru

Paper 4 - Royal College of Paediatrics and Child Health

## Break (11.40 - 11.50)

## 4 Supporting people with chronic conditions: evidence session with the Royal Pharmaceutical Society

(11.50-12.30) (Pages 55 - 58)

Chris Brown, Royal Pharmaceutical Society Expert Member

Elen Jones, Royal Pharmaceutical Society Director for Wales

Paper 5 - Royal Pharmaceutical Society

## 5 Paper(s) to note

(12.30)

**5.1 Letter from the Chair to the Rt Hon David TC Davies MP, Secretary of State for Wales regarding the Welsh Government draft budget for 2024-25**

(Page 59)

**5.2 Response from the Rt Hon David TC Davies MP, Secretary of State for Wales to the Chair regarding the Welsh Government draft budget for 2024-25**

(Page 60)

5.3 Letter to the Chairs of the Health and Social Care Committee and the Public Accounts and Public Administration Committee from the Minister for Health and Social Services regarding the Oversight and Escalation Framework

(Pages 61 - 62)

5.4 Letter to the Chair from the Royal College of Nursing Wales regarding the introduction of the role of the Registered Nursing Associate in Wales

(Pages 63 - 75)

5.5 Letter to the Chair from the Minister for Health and Social Services regarding the launch of the 'Putting Things Right' consultation

(Page 76)

5.6 Letter to the Llywydd and Chair of Business Committee from the Chair, Economy, Trade and Rural Affairs Committee regarding holding an additional meeting on 14 March 2024

(Pages 77 - 78)

5.7 Follow-up response from Digital Health and Care Wales to the Chairs of the Health and Social Care Committee and Public Accounts and Public Administration Committee regarding the scrutiny of Digital Health and Care Wales

(Pages 79 - 80)

5.8 Letter to the Chair from the Minister for Health and Social Services, the Deputy Minister for Social Services and the Deputy Minister for Mental Health and Wellbeing following the scrutiny session on the Welsh Government draft budget for 2024-25

(Pages 81 - 87)

5.9 Letter to the Chair from the Deputy Minister for Mental Health and Wellbeing following the scrutiny session on the Welsh Government draft budget for 2024-25

(Pages 88 - 90)

## 6 Motion under Standing Order 17.42 (ix) to resolve to exclude the public from the remainder of the meeting

(12.30)

## 7 Supporting people with chronic conditions: consideration of evidence

(12.30–12.40)

## 8 Areas of Research Interest (ARI): innovation for improvement in healthcare

(12.40–12.45) (Pages 91 – 92)

Paper 6 – Areas of Research Interest (ARI): innovation for improvement in healthcare

## 9 Forward work programme

(12.45–13.00) (Pages 93 – 115)

Paper 7 – Forward work programme

## 10 NHS waiting times monitoring report

(13.00–13.10) (Pages 116 – 132)

Paper 8 – NHS waiting times monitoring report

## 11 Gynaecological cancers: consideration of Welsh Government response

(13.10–13.30) (Pages 133 – 158)

Paper 9 – Welsh Government response

Paper 10 – Research brief – analysis of Welsh Government response

## 12 Nurse Staffing Levels (Wales) Act 2016: post-legislative scrutiny: consideration of draft report

(13.30–14.00) (Pages 159 – 202)

Paper 11 – draft report

# Agenda Item 2

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Senedd Health and Social Care Committee Inquiry:

## Supporting people with chronic conditions

ADSS Cymru
Yn arwain Gwasanaethau Cymdeithasol yng Nghymru
Leading Social Services 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 All-Wales Heads of Children's Service (AWHOCs), the All-Wales Adult Service Heads (AWASH) 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.

## General Comment

ADSS Cymru welcomes the opportunity to contribute to the Health and Social Care Committee's inquiry into supporting people with chronic conditions. A key driver within both the *Parliamentary Review of Health and Social Care in Wales* and *A Healthier Wales*, was that a medical/clinical model of health, and a separate system of social care, is not a model for delivering high quality, person-centred care fit for the future. Moreover, the expectation in both documents, whether that is the focus on the 'Quadruple Aim' in the Parliamentary Review or on the set of 'Once for Wales' design principles in a Healthier Wales, is that the most significant opportunity to create a system fit for the future is if we shift the balance of our health and care system towards earlier detection and intervention, which is designed to prevent illness and prolong independence. By doing this and ensuring people have a greater stake in managing their own health and wellbeing in the process, we will have a more sustainable and resilient health and care system, as well as improved public health outcomes for the citizens of Wales.

Lifestyles and people's expectations of wanting to do and achieve more in life has continued to progress and evolve. People with complex health conditions, physical disability or impairment, are living longer because medicine is doing so much more to allow them to live and experience good quality of life. Coupled with this is the fact that technology is also transforming the way we live, allowing diagnostics, treatment and monitoring to take place

away from clinical settings and into hubs in the community and even into people's own homes. Treating people in hospitals when they are symptomatic is only a small part of a modern health and social care system. Keeping people well, independent and resilient at home, in their community, is an outcome a fully integrated health and social system must strive to achieve.

## What is the role of social care in supporting people with chronic conditions?

As leaders in social care, we know the sector plays a crucial role in supporting both children and adults with chronic health conditions, by providing a range of services that aim to enhance their overall well-being, independence, and quality of life. Some of the ways in which social care supports individuals with chronic health conditions, includes:

1. Assessment and Care Planning: Social care professionals assess the strengths, capabilities and needs of individuals with chronic health conditions to develop personalised care plans. These plans take into account the specific challenges posed by the condition and outline the support required, such as assistance with personal care, mobility, medication management, and emotional support.

2. Personal Care: Social care providers offer assistance with daily activities such as bathing, dressing, meal preparation, and managing medication. This support helps individuals with chronic health conditions maintain their personal hygiene, nutrition, and medication adherence.

3. Coordination of Care: Social care professionals communicate and collaborate with healthcare providers, community third sector organisations, and other relevant stakeholders to ensure a coordinated and holistic approach to care. They help individuals navigate the healthcare system, manage appointments, and coordinate different aspects of their care to promote continuity and effectiveness.

4. Emotional and Psychological Support: Living with a chronic health condition can be emotionally challenging. Social care workers provide emotional support, counselling, and personal empathy to help individuals cope with the psychological impact of their condition. They may also facilitate support groups or connect individuals with appropriate mental health services.

5. Socialisation and Community Integration: Social isolation is a common issue for individuals with chronic health conditions. Social care services offer a range of day opportunity activities and support groups to encourage socialisation and combat

loneliness. They may also help individuals connect with local community resources and organisations that cater to their specific needs.

6. Support for Carers and Family Members: Social care recognises the important role of unpaid carers and family members in supporting individuals with chronic health conditions. They assess individual need and provide guidance, respite care, and training for unpaid carers to ensure they have the necessary skills and knowledge to provide effective care while also addressing their own well-being.

7. Advocacy, Information and Advice: Social care professionals can act as advocates for individuals with chronic health conditions, helping them access appropriate healthcare services, benefits, and support systems. They provide information and guidance on available resources, rights, and entitlements, empowering individuals to make informed decisions about their care.

8. Housing and Accommodation Support: Social care services can work collaboratively with colleagues in other local government departments, to assist individuals in finding suitable housing options that accommodate their specific needs, such as accessible housing or supported living arrangements. They may also provide support with home modifications or assistive technology to promote independent living.

All these elements focus on enabling people to live and, in some circumstances, die well, with their chronic conditions.

New models of care have been developed which recognise the complexities of managing care where there is overlap between the wider community, the health care system and provider organisations, for example, the Expert Patient Programme. These new models indicate a shift away from the idea of chronically ill people as passive recipients of care, towards active engagement, in partnership with health and social care professionals, in managing their own personal care needs.

This partnership, ideally, involves collaborative care and self-management education because for effective person-centred care to be established, individuals should be able to discuss their own ideas about self-care actions, including lifestyle management, in an open and thorough way. If they are unable to achieve that independently, then they should be enabled to have these What Matters conversations through the supported advocacy.

Crucial to enabling personalised, self-managed care, is the need for individuals to have information from the point of diagnosis. It is important that the individual, and where appropriate, their unpaid carers and family members, have active participation during those

initial encounters with health and care practitioners. For self-care needs to be addressed, opportunities for individuals to talk about their diet, routines and lifestyle management, need to be incorporated into the encounter. Care plans can help to facilitate this discussion. However, what is vitally important to support individuals with their self-care management is the recognition of the value of the person's knowledge and experiences.

## Supporting a child with chronic health conditions

It is essential that we understand the daily lived experiences of a child to inform care planning. Whilst the voice of the child is important in developing self-managed care support, in the context of their age and stage of development, the voice of the carer is also crucial. Managing the physical and emotional needs of a child with a long-term health condition can be highly demanding for unpaid parent carers, particularly for older parents, who may have health issues of their own and parent carers who have other children they have a caring responsibility for. Young carers also play an important role in supporting siblings with chronic health conditions which can have a significant impact of their health and wellbeing.

Children with common chronic health conditions are twice as likely to suffer from emotional problems or disturbed behaviour especially if their condition affects their brain. There are also specific challenges for children who have suffered neglectful childhoods. These children are more frequently diagnosed with chronic conditions linked to poor parental care. Many will also have other behavioural needs as a result of attachment issues and traumatic experiences they have faced.

There is an increasing recognition that some long-term conditions caused by neglect and abuse, such as Foetal Alcohol Syndrome, are under diagnosed. Such health conditions can be difficult to diagnose, and it can be impossible to predict their long-term impact or what support might be needed in the future. Under diagnosis can be a barrier to children and their carers accessing the right support at the right time.

Children with long-term health conditions often need daily on-going medication and monitoring. Their condition can lead to them being away from school for long periods of time which can result in their learning being delayed.

At school and around other children, a child might feel that their condition makes them different to others and as a result develop anxieties about their condition and compromise their mental health. They might have fewer opportunities to learn everyday skills and to develop their interests and hobbies. Some children have barriers to engaging in treatment or care due to their traumatic experiences. As they move into adolescence, their behaviour can become unpredictable and unsafe, which leaves them at risk to complications of not taking medication or following treatment. Moreover, not accessing diagnosis and treatment in a

timely way can increase their likelihood of involvement with the criminal justice system, which can have a detrimental impact in their future adult life. Therefore, it is crucial that a multi-Disciplinary approach is undertaken between health and social care professionals so that the child and their parent-carer/guardian feel supported.

## Identification of key themes for the Committee to explore

ADSS Cymru believes that the inquiry needs to examine a number of key themes and factors in its work to ascertain whether the mechanisms that are in place to support both children and adults with chronic conditions are robust, sufficient and operate well in practice.

Understanding the myriad of complexities that are at play is crucial. Chronic diseases, including cardiovascular disease, cancer, chronic respiratory diseases and metabolic syndrome (hypertension, diabetes, dyslipidaemia) have been on the increase in the UK over recent decades and result in a substantial economic and social burden.

Added to this is the expediential rise of people will chronic mental ill-health and poor mental well-being. This has been exacerbated following the impact of the COVID-19 pandemic. The knock-on impact to society is that for many of our children, we have seen an increase in traumatic stress, leading to more behaviours that challenge and for our young people, the taking of greater lifestyle risks, like substance misuse. For adults, particularly older adults, we are seeing higher levels of substance use disorders, emanating from the impact of the abuse of alcohol, as well as a wide range of social and prescription drugs.

These factors not only directly contribute to additional demand in the system, which has been considerably outstripping the supply of health and care support that can be provided but they also provide health and social care professionals with complex scenarios that need to be overcome with resolutions broader than just lifestyle advice and signposting.

## What are the barriers to optimised levels of support?

### COVID-19 Impact

The COVID-19 pandemic has brought into sharp focus not just the essential value that social care plays to society but also the myriad of challenges that currently face the whole social care sector in Wales.

It is widely accepted that key areas of social service functions are experiencing challenges in a system that is facing unprecedented levels of complexity and demand. This, combined with fundamental workforce shortages, has exposed an already fragile situation. The reasons for this include:

- Pent up demand suppressed during the COVID-19 pandemic and periods of Lockdown causing significant pressures on systems and escalations in need when demand is not met in a timely preventative manner.
- Increased complexity and frailty in older people from reduced prevention, medical care, increased waiting lists and a greater level of community isolation
- Pressures in the primary care system restricting access to key healthcare professionals and timely diagnostics that can reduce the escalation of healthcare need through early intervention
- A vicious cycle of delay and deconditioning/decompensation in hospital because of delays and shortages in key healthcare roles to ensure timely discharge
- Exhaustion across the social care workforce with more frequent early retirements and people leaving the sector to pursue other careers
- Increased wages and competition from sectors such as retail and hospitality
- Difficulty in recruiting and retaining social workers – particularly in children's services - in sufficient numbers across the sector and systemic challenges in working with agencies both in terms of cost and competence.

Specifically in children's services, we have seen not just an increased demand for services but the sheer complexity of those support needs, particularly in mental health and emotional well-being, is vast. These issues are now being further exacerbated by the cost-of-living crisis, which is placing extreme pressure on individual and family finances. We are already seeing the associated increases in poverty, unemployment, isolation, domestic abuse, family breakdown, anti-social behaviour and homelessness. These issues make it very difficult to effectively support and manage the needs of children with chronic conditions. The consequence is that more children, young people, and parents will require more services across the spectrum of need.

## Financial Pressures

The Welsh Government have identified that the health and social care system is under significant pressure. Whilst we welcomed the increased uplift of £165m, accompanied with the recurrent provision of £70m for the Real Living Wage in the Government's 2023-24 budget, it is evident that very difficult choices will have to be made in relation to continued service provision.

We know from survey work undertaken in the autumn of 2022 by the Welsh Local Government Association (WLGA) in collaboration with our members and the Society of Welsh Treasurers (SWT), that forecasts indicate that social care across Wales is facing a considerable financial challenge in 2023-24 and 2024-25. The pressure in both adults' and children's

services includes the challenge of recruitment and retention of staff with this issue also affecting commissioned services from providers.

Local authorities are projecting an estimated total cumulative pressure for social services of £407.8m for 2023-24 and 2024-25. Within this overall social services total, the estimated total commissioning cost and demand pressures are £288.4m, with a pay inflation pressure totalling £75.8m for the two years.

**Summary of Social Services Pressure 2023-24 and 2024-25**

| | 2023-24 | 2024-25 | Total |
|---|---|---|---|
| | £000s | £000s | £000s |
| Pay inflation pressures | 51,858 | 23,918 | 75,776 |
| Non pay inflation pressures | 20,712 | 12,423 | 33,135 |
| Fees/charges inflation | (2,677) | (2,192) | (4,869) |
| Commissioning cost pressures - Adults | 86,939 | 55,201 | 142,140 |
| Commissioning cost pressures - Children's | 14,066 | 10,449 | 24,515 |
| Demand related pressures - Adults | 35,980 | 29,462 | 65,442 |
| Demand related pressures – Children's | 37,235 | 19,104 | 56,339 |
| Reduction in specific grants | 5,914 | 1,646 | 7,560 |
| Local priorities | 4,418 | 1,651 | 6,069 |
| Other | 1,699 | 0 | 1,699 |
| **Overall Total** | **256,144** | **151,662** | **407,806** |

Source: WLGA/SWT Survey September 2022

Further detail and commentary on our financial concerns can be found in our response to the Senedd's Finance Committee scrutiny of the Welsh Government's Budget of 2023-24.

However, it is clear that with wider concerns about NHS financial pressures due to waiting list demand, acute care demand and the increases in day-to-day running costs due to inflation, energy increases etc., a whole systems change is required. We need to move away from dealing with acute need to the effective management of chronic conditions in the community – in its broadest sense. There needs to be a focus on early access to health and social care professionals, so that timely diagnosis can be made, leading to the right size package of care and support being put in place quickly. Essentially, right time, right place, right professional at pace.

## Workforce

The impact that the COVID-19 pandemic has had on the social care workforce has been wide-ranging and profound. The lustre of public support during the pandemic has long since faded and the workforce that remains feel exhausted, unappreciated and are questioning their long-term future in the sector. The issue of workforce recruitment and retention is widely regarded as an unprecedented, existential crisis for the whole social care sector; a crisis which has the

potential to hinder and undermined the sector's renewal and lead to suboptimal outcomes for individuals with chronic conditions.

This is not just a crisis facing in-house service provision, but it is also impacting independent commissioned provision as well. For example, there is a lack of capacity to undertake assessments to provide packages of care that are needed and there is a lack of Occupational Therapists and other multi-Disciplinary professionals to support people to live well and independently in the community.

Social care departments within local government have maintained a constant recruitment programme across Wales which has seen some success, but the market remains very volatile for both qualified and unqualified positions. Moreover, the resilience of the current workforce supporting children's services is also of significant concern. The challenges include:

- Difficulties in recruiting qualified childcare social workers - a recurrent theme over many years but this has markedly worsened
- Difficulties in finding quality agency social workers and ever-increasing agency fee levels
- A lack of both educational psychologists and mental health practitioners
- Competition between local authorities and other statutory services for key social worker roles
- Newly qualified social workers having to take on incredibly complex caseloads because of a lack of team capacity
- Significant pressures in respect of high levels of unexpected absence and staff sickness; none of which could have been predicted or planned for.
- Social workers stepping down from the profession into non-professional roles due the immense strain – consequently adding to the strain on the remaining workforce
- Staff that remain in the system becoming increasingly fatigued, both emotionally and physically.

The consequential impact of this capacity shortfall is an increase in agency related costs, which has added further financial pressure to local authority budgets, and we have seen a greater burden of responsibility and expectation fall on the shoulders of unpaid carers.

We believe workforce pressures in health and social care need to be examined as part of this inquiry because it is hampering the system's ability to deliver high-quality, integrated, person-centred support to individuals with a chronic condition.

## Seamless Integration - the relationship between health and social care

The relationship between the NHS and social care is an important one when it comes to helping an individual manage their chronic condition. Without well planned care and the right interventions by the right professionals at the right time, people's conditions can quickly become destabilised. The consequence is often the individual experiencing acute need and requiring significant intervention to rebalance both physical health and mental wellbeing. Such episodes can severely damage people's confidence to live independently. This then creates a knock-on effect on so many other health and social care services already under intense pressure.

At the same time, a lack of capacity and resources in health also has implications for local authorities. For example, a lack of resources to progress individuals with a high level of complex needs where consideration of Continuing Health Care (CHC) is required; some of these packages are £150k to £250k per annum. There is a similar situation in children's services, where there are an increased number of children with complex care needs in need of assessment for Children and Young People's Continuing Care (CYPCC). Local authorities have reported that health boards' capacity to assess and arrange provision for these children and young people means that local authorities continue to have to meet their needs, requiring the use of specialist children looked after placements. We believe that operational delivery and governance functions around CHC and CYPCC needs to be examined in this inquiry because we believe it is damaging partnership relationships and ultimately, hampering care outcomes for individuals with chronic conditions, even for those in receipt of end of life care.

A significant investment into social care is required to help resolve some of these issues, but it is essential that social care is not just seen as a service simply there to support the NHS. There is a need to recognise the value social care has in its own right. However, where the NHS and social care work well together, there is potential to keep people well and reduce demand on secondary health services. There is also evidence that interventions like reablement have the potential to prolong people's ability to live at home and reduce or even remove the need for care. However, greater clarity on joint funding arrangements and their governance is required to ensure that people are front and centre of service provision not budgets.

Social care is also essential because it links to a wide range of other services that can support people's wellbeing such as work, housing, social interaction and a good environment. Ultimately, the greatest impact on health and wellbeing is in addressing the wider determinants of health and ensuring that local government has the power, flexibility and resources to fulfil its core purpose of ensuring that all our residents have the opportunities to have the best start in life, to live well and age well.

## Conclusion

The inquiry Terms of Reference rightly point out the complex nature of supporting people with chronic conditions. The perspective of social care leaders post-pandemic is that we need to refocus on the key principles in the Social Services and Well-being (Wales) Act 2014 and in A Healthier Wales. That means statutory providers and associated partners concentrating solely on the individual to deliver, high-quality, strengths-based and seamless care and support. However, we need a health and care system that moves away from acute, symptomatic, reactive care to one based on earlier detection and intervention. Only by ensuring that people see the right professional, at the right place, at the right time, we will see improved self-management of personal health and well-being, as well a health and social care system more resilient and able to provide that support.

# Agenda Item 3

**British Geriatrics Society**
Improving healthcare for older people

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Russell George MS

Chair, Health and Social Care Committee

Senedd Cymru

Cardiff Bay

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CF99 1SN

25 May 2023

Dear Mr George,

**Supporting people with chronic conditions – response from the British Geriatrics Society**

The British Geriatrics Society (BGS) welcomes the opportunity to contribute to this important consultation about supporting people with chronic conditions. The BGS is the membership organisation for all healthcare professionals engaged in the treatment and care of older people across the UK. Since 1947 our members have been at the forefront of transforming the quality of care available to older people. Our vision is for a society where all older people receive high-quality patient-centred care where and when they need it. We currently have over 4,600 members across the UK, including around 200 in Wales. This submission has been developed by members of the BGS Wales Council which is comprised of healthcare professionals working with older people across Wales. We have structured our response around the broad areas set out in the consultation document.

**NHS and social care services**

- *The readiness of local NHS and social care services to treat people with chronic conditions within the community.*

Many NHS services are focused around the acute hospital, which is not where most people with chronic conditions are or need to be. There is a need to move more services into the community to be provided to people in the place they call home or near to it. While there have been moves in recent

years to provide more services closer to home through community resource teams, Hospital at Home and virtual wards services, there is a well-documented need for further investment in this type of care.[1] Many areas, however, do not have the workforce required to provide these services in the community. The NHS and social care workforce are already stretched beyond capacity and without addressing this, it will be impossible for the NHS and social care to provide good-quality care in the community to people living with chronic conditions. The services need to acknowledge care giver burden. Care giver burden is the perception of strain and stress resulting from perceived obligation to provide care to loved ones. Careful consideration needs to be given to support given to families while providing care and support near to their homes.

- *Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.*

While chronic conditions can affect people of any age, it must be acknowledged that the vast majority of people with chronic conditions are older people – 58% of people over 60 are affected by a chronic condition compared to only 14% of those under 40.[2] It is therefore essential that access to services for people with chronic conditions is set up with older people in mind. Many older people have limited mobility and therefore may struggle to travel to appointments. In addition, many older people have more than one chronic condition and will struggle to travel to multiple appointments for each condition.

It is also important to note that around 20% of pensioners in Wales live in relative income poverty.[3] People living in poverty are also more likely to have chronic conditions with a 60% higher prevalence of chronic conditions in the poorest social class when compared to the richest social class.[2] Those living in poverty are likely to experience more challenges in accessing care for their conditions.

While IT solutions such as virtual appointments for clinical review and assessments may be an option for some people, older people with chronic conditions may not have the equipment or knowledge to access services in this way. While digital literacy among older people is increasing, this group is still one of the most likely groups to be digitally excluded. It is important that digital solutions are not relied upon and that older people who do not have access to digital technology are still able to access the care that they need, in a format that is appropriate to them.

**Multiple conditions**

- *The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.*

The NHS has been set up to treat people on a condition-by-condition basis and, in most cases, still operates in this way. This particularly applies to hospital care which is arranged on a specialty basis. This is not conducive to providing high-quality, patient-centred care as it can mean that patients are required to attend multiple appointments and repeat themselves constantly to different healthcare professionals. Comprehensive geriatric assessment (CGA) should be available to older people with chronic conditions to ensure that their treatment is appropriate to them. CGA is a multidimensional approach which includes physical, cognitive, functional, social and psychological components and is the gold-standard of assessment for older people. Systems should have the capacity to deliver CGA to all older patients.[4]

In addition, there needs to be a recognition across the NHS in Wales that most healthcare professionals (with the exceptions of those working in child and maternal health) will be caring for older people more than any other patient group. For this reason, healthcare professionals across all specialties and disciplines should know how to care for people with frailty, cognitive impairments and other conditions associated with ageing, alongside their own area of expertise.

- *The interaction between mental health conditions and long-term physical health conditions.*

People with chronic or long-term conditions are more likely to experience serious mental health problems, and vice versa. More than a quarter of those with one or more long-term physical health condition will also have a mental health condition and of those with symptoms of serious mental health problems, 37.6% also have long-term physical conditions.[5] As the BGS highlighted in our submission to this Committee's inquiry into mental health inequalities,[6] mental health services for older people in Wales are currently in crisis. Services are not currently available to guarantee people who have mental health conditions alongside long-term physical conditions are able to access the care and support they need to manage both their mental and physical health adequately.

**Prevention and lifestyle**

- *Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).*

It is important to recognise that prevention and early intervention are important at all stages of the life course, not just in younger age groups. Prevention is a cornerstone of geriatric medicine with experts in older people's healthcare continuously working to prevent their older patients from becoming ill, being admitted to hospital or returning to hospital once they have been discharged. There is also good evidence that interventions through 'anticipatory' or 'proactive' care can be beneficial for many older people. These services work to identify people at risk of developing frailty or people with mild frailty

who are at risk of deteriorating and provide proactive care to prevent or reverse the onset of frailty. This enables people to live independently for longer.

- *Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.*

While it is never too late for older people to make positive changes to their lifestyles, they may face challenges to doing so. For example, older people who drink alcohol at a harmful level may experience difficulty in accessing the services that they need and may not be identified as drinking too much. This issue exists both with NHS staff failing to assess for alcohol problems when - for instance - an older person attends an emergency department after a fall, and with family members who may excuse excess alcohol consumption as a comfort later in life.[7]

Physical activity is incredibly important for older people as it helps to reduce incidence of frailty, prevent falls and prevent other illness. People who are physically active are also more likely to recover quickly from periods of ill health and have improved mental health and cognition. However, many older people are not regularly physically active and are not sufficiently supported to be physically active. It is important that older people are able to access physical activity that is appropriate to them and are supported to be active as often as they are able.[7]

While there is understandably a focus on a prevention of obesity across the population, it is important to note that many older people face a loss of appetite as they age and may lose more weight than is healthy. Older people must be supported to continue to shop for nutritious food and to eat well as they approach later life.[7]

**Impact of additional factors**

- *The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.*

BGS members report that the cost of living crisis is having an impact on many older people, particularly during the last winter. As described above, many older people in Wales are living in poverty and this will have worsened over the last year as many people across the country have experienced extreme financial hardship. BGS members report older people failing to attend appointments as they are unable to afford the bus fare to travel there, limiting the number of meals they eat every day and heating only one room in their home.[8] The cost of travelling to appointments is of particular concern for those with multiple chronic conditions as they may be required to attend numerous appointments with the cost of travel becoming prohibitive for some.

- *The extent to which services will have the capacity to meet future demand with an ageing population.*

Current services do not have the capacity to meet the demand that is already being created by the ageing population. The number of people in Wales aged 65 and older is projected to increase by 16.1% between mid-2020 and mid-2030 with the over 75 population projected to increase by 23.9% in the same period.[9] One in three people aged over 85 require support with one or more activities of daily living.[10] Currently there are not enough people working in the NHS and social care to provide care for this growing population group. In order to provide high-quality care to all older people who need it, the older people's healthcare workforce will need to be increased significantly. As the Welsh Government considers how the NHS and social care services are staffed in the future, the needs of older people should be kept central to their thinking. Older people are the biggest user group of health and care services and if services work well for older people, they are more likely to work well for other groups. The BGS welcomes the Welsh Government's publication of *Six goals for urgent and emergency care*[11] and would like to emphasise the need to support people with right care at right place when they are acutely unwell and investment in the establishment of adequate Frailty services across the NHS in Wales.

Thank you for the opportunity to contribute to this important inquiry. If you wish to discuss any aspect of our submission or to invite a member of our Wales Council to give oral evidence to the committee, please contact our Policy Manager, Sally Greenbrook [redacted] to make arrangements.

Yours sincerely,

Professor Sam Abraham
Chair, BGS Wales Council.

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# Diabetes UK Response

**Written by**: Mathew Norman, Deputy Director (Wales)

**Submitted as**: Submission as an organisation.

**Authorisation to publish the submission:** Happy for the submission to be published as Diabetes UK Cymru.

**About us**

Diabetes UK's vision is a world where diabetes can do no harm. We lead the fight against Wales' largest growing health crisis, which involves us all sharing knowledge and taking on diabetes together.

Over 207,295 people live with diabetes in Wales, equivalent to 1 in 13 people, the highest level of prevalence of any of the UK Nations. The last twenty years have seen a rapid increase in the diagnosis of diabetes; this is due in part to a growing rate of type 2 diabetes diagnoses, with an estimated 65,000 people in Wales living with undiagnosed type 2 diabetes. The biggest cause of

The continued prevalence of obesity suggests that an estimated 580,000 people in Wales could be at risk of developing type 2 diabetes, the most common form of diabetes, accounting for 90% of all cases. By 2030 the number of adults with diabetes in Wales will likely grow from 8% to 11%.

Further information on diabetes can be found on our website.

**Response**

We thank the Committee for the opportunity to respond to the inquiry into Supporting People with Chronic Conditions. To assist the Committee, we have responded under headings identified in the consultation:

- NHS and Social Care Services
- Multiple Conditions
- Impact of Additional Factors, Prevention and Lifestyle

In our response, we would like to note our thanks and support for the continued hard work and dedication that our NHS and Social Care workers provide. We highlight the experiences of people living with diabetes and the current data available and note that this is not a reflection on the dedicated workers of the NHS who support people living with diabetes and aim to deliver excellent level of care.

**NHS and Social Care Services**

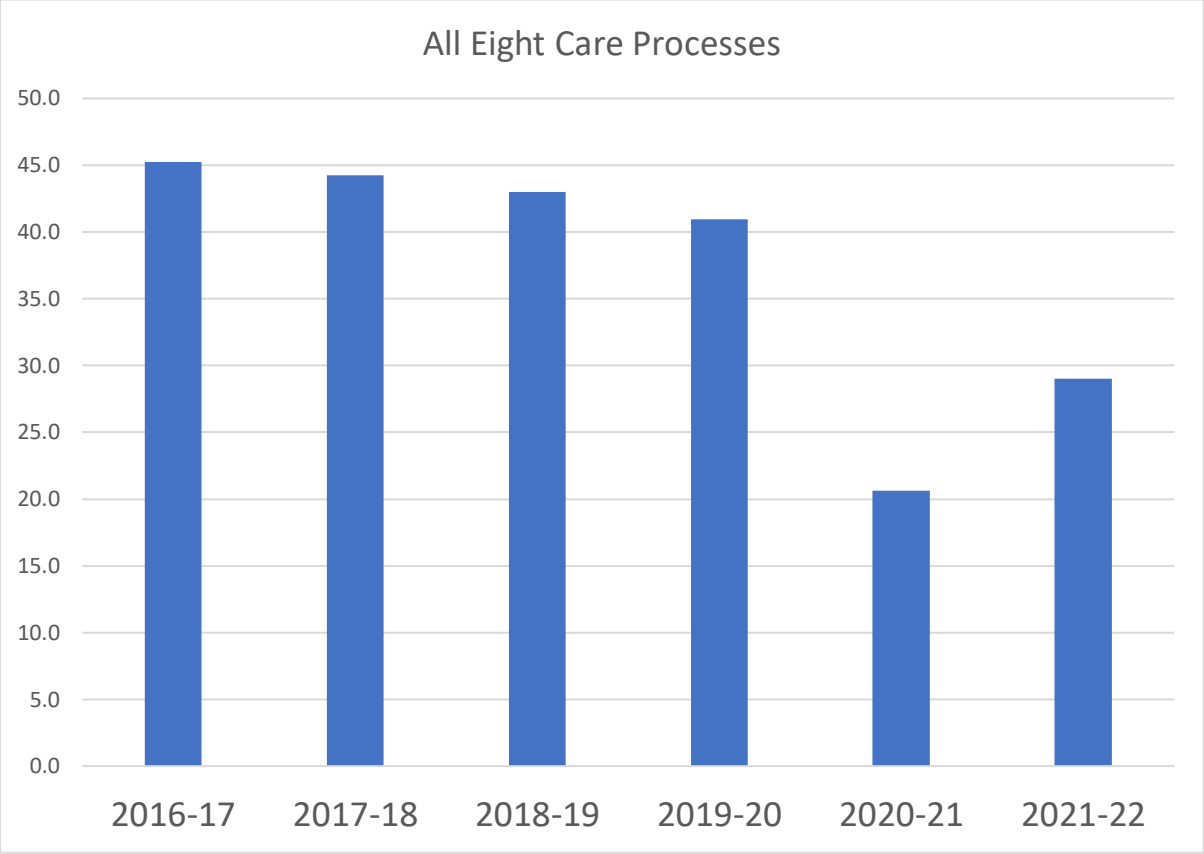
One of the means and ways to review the current level and status of care for people living with diabetes in Wales is the National Diabetes Audit (NDA). NDA data is a measure of the effectiveness of delivery of diabetes care against NICE guidelines; the data is crucial in monitoring, identifying, and recognising good and less good care across Wales. With the most recent report from the National Diabetes Audit to be published in a month, the most recent comprehensive review of diabetes care in England and Wales was published in July 2022.[i]

The National Institute for Health and Care Excellence (NICE) recommends nine care processes for people living with type 1 and type 2 diabetes. However, due to temporary service closures during the pandemic retinal screening is not compared. Therefore, eight care processes compared across both type 1[ii] and type 2[iii] diabetes are highlighted in the latest NDA report.

Unfortunately, combining care management results of people living with both type 1 and type 2 diabetes shows that less than a third (29%) received all of their vital checks in 2021/22. Before the pandemic in 2019/20, the figure was 41%.

England has recovered much more quickly, where the same measurement of checks currently sits at 47% in 2021/22 compared to 57.3% in 2019. The recovery rate in Wales to meet management checks for people living with diabetes is not the same as in England and is falling behind.

Diabetes UK Cymru is concerned by the lack of recovery compared to trusts across the border and notes that a declining trend in meeting the care processes in Wales was apparent before the pandemic. The graph below notes the results of the last six annual NDA reports for Wales, from 2016/17 to the most recent 2021/22.




*Compiled from NDA reports[iv]

What is apparent is the downward trend in meeting the care processes in Wales and the challenge ahead of not only restoring the overall percentage of people living with diabetes managing their diabetes well to pre-pandemic levels but also reversing the downward trend seen before the pandemic began. Failing to meet these essential yearly checks can cause further complications and problems for people living with diabetes, such as sight loss and amputations which in turn reduces the quality of life of people living with diabetes and increases pressures on the NHS and Social Care Services. When completed, any potential early warning signs can be acted on quickly, and referrals

can be made to new treatments and support, such as access to new technologies. This can improve the overall well-being of someone living with diabetes and support clinicians in managing a person's diabetes.

Further, the NDA report noted:

- Risk ratios of mortality compared to those without diabetes continue to increase in Wales for men and women living with type 1 and type 2 diabetes.[v] The mortality risk rates correlate with Diabetic Ketoacidosis (DKA) mortality rates which also continue to increase and have done so significantly in the three most recent available data sets for Wales (2017 – 2020).[vi]
- Recorded high levels (86 mmol/mol or greater) of HbA1c (average blood glucose levels) continue to be recorded higher in young adults in Wales compared to England, whilst Wales and England are on par for recorded lower safer levels (58 mmol/mol or less).[vii]
- The risk of Angina for males living with type 1 and type 2 and females with type 2 diabetes continues to increase compared to the general population. Levels of risk for females with type 1 diabetes have decreased compared to the general population.
- Whilst risk for stroke has increased for men and women living with type 2 diabetes compared to the general population and decreased for people living with type 1 diabetes.
- Women living with type 1 diabetes saw an increase in the level of risk of CVD (Cardio Vascular Disease) compared to the general population.[viii]

Earlier this year, Diabetes UK asked people living with diabetes to complete a survey as part of its Diabetes is Serious Campaign (DIS). The survey was open from the 25th of January 2023 until the 20th of February 2023 and was pan UK. In Wales, 698 responses were received, with 520 providing a valid postcode for analysis.[ix] One aspect of the survey was asking people living with diabetes about their diabetes management.

Unfortunately, over half of the respondents (55%) experienced difficulties managing their diabetes in 2022. Respondents from the most deprived areas were more likely to record difficulties, with these respondents more likely to attribute these difficulties to the rising cost of living.

When asked what difficulties they faced when managing their diabetes, the most common cause was lack of access to healthcare teams, including lack of access to emotional and psychological support. Our respondents' reports of lack of access to their healthcare teams support the data presented by the NDA since core processes to manage their diabetes are not being met.

To elaborate further, we asked respondents in our DIS survey to respond on their access to care. Unfortunately, we found that:

- More than a third (41.0%) of respondents found it difficult to make appointments for their diabetes checkups.
- More than half (52.4%) who had tried to get emotional or psychological support faced difficulties doing so.
- People in the most deprived quintile were 30% more likely to have had no contact with their healthcare team in over a year than those in the least deprived.
- In over a year, 1 in 8 people in the most deprived areas reported no contact with their healthcare team.

When asked for the reason why there was a lack of contact, 60% of respondents noted that they had not been contacted by their healthcare professional regarding their diabetes, with over 40% noting that when appointments were arranged, they were either delayed or cancelled.

One of the most effective ways and means for someone living with diabetes (primarily type 1 diabetes and type 2 dependent on insulin) to manage their diabetes well is access to technology. These can vary from Flash Glucose Monitoring, Continuous Glucose Monitoring (CGM), Insulin Pumps, Hybrid Close Loop, and open source /DIY closed-loop technology.[x]

Our DIS survey asked our respondents (living with type 1 diabetes) how technology helped them manage their diabetes. 85.0% of respondents with type 1 diabetes using technology agreed it helped them to manage their diabetes in 2022, and 75.4% said it improved their overall well-being. Furthermore, 60.0% of respondents informed us that diabetes technology made remote consultations with their diabetes team easier. Technology is changing the way that people living with diabetes live their lives and reduces pressures associated with the condition that can further cause complications.

Sensor technology for Type 1 diabetes has been available in the Welsh NHS since November 2017. What some may find challenging in obtaining monitoring technology in Wales will be the eligibility criteria. For example, referral to Flash glucose testing is an option that requires consideration of several factors, such as the frequency of blood glucose testing in a day, more than one episode of severe hypoglycaemia, or frequent asymptomatic hypoglycaemia.

On the 31st of March 2022, NICE guidelines were updated, which changed the eligibility criteria.[xi] Changes in NICE guidelines will support referrals for this monitoring technology; in essence, it is a shift in thinking that recognises technology as an integral part of diabetes management. The choice will be based (according to NICE) on shared decision-making with the individual based on preferences, needs, characteristics and the functionality of the devices available.

However, new NICE guidelines don't immediately translate into the latest recommendations being adopted as policy. In a written question response to Hefin David MS on the 22nd of April 2022, the Minister for Health and Social Services, Eluned Morgan MS, cited staff training obligations as a possible obstacle to implementing the updated NICE guidelines.[xii]

On the 8th of November 2022, Joel James MS asked if the First Minister would provide an update on the qualifying criteria for flash and continuous glucose monitoring technology for diabetes management.[xiii] In response from the Welsh Government, the Minister for Rural Affairs and North Wales and Trefnydd Lesley Griffiths MS noted the importance of the accessibility of such technologies in Wales. With the Minister of Health and Social Services in the Chamber, it was noted that she would write to Joel James MS with a response on the current rollout of the NICE Guidelines.

Diabetes UK Cymru has been waiting for the Minister's response and working with the Cross-Party Group on Diabetes and Members to highlight the issue. An imminent NICE update on the use of Hybrid Closed Loop systems for managing blood glucose levels in type 1 diabetes is due to be published soon. We expect that updated guidelines will improve access for people living with diabetes using insulin pump or CGM technology to Hybrid Closed Loop technologies that drastically support people living with diabetes to help them manage their condition.

In our DIS survey, we learnt that only 31% of respondents use CGM, and 26% use insulin pump technology in Wales.

With the Quality Statement on Diabetes to be announced in June, we hope to learn more about the continued support and rollout of technologies for people living with diabetes in Wales.

**Multiple Conditions**

In our recent DIS survey, we asked people living with diabetes if they had elective surgery with the NHS in the previous two years. 12.2% of respondents stated they had, and of those respondents, whilst waiting for elective surgery, nearly 30% stated that it became more difficult to manage their diabetes.

Further, we asked respondents if they were currently on a waiting list for elective surgery; 11.9% of respondents indicated they were, and out of those respondents, one in ten had their surgery delayed because of their HbA1c levels, which could be due to the management of their diabetes affected either by waiting for their elective surgery or by other reasons (as noted earlier).

Our survey further highlighted the impact that waiting lists for elective surgery had on the management of their diabetes, which in turn affects the NHS and increases pressures on other services. For respondents waiting for elective surgery, we asked them what further impact this had on managing their condition. 40% indicated that they needed to visit their GP more to manage their condition, whilst 17% indicated that they have had to visit A&E to manage their condition.

We lastly asked the same respondents if they have had to pay for private care to manage their condition as they wait for surgery. 11% indicated that they had, with a further 36% considering seeking private medical care to have their surgery. This is an alarming development as people living with diabetes struggle to manage their condition because they are waiting for surgery; they are either seeking or considering private care, highlighting the direct impact that the pressures of the NHS are having on people living with lifelong health conditions.

It is also more than likely that this wait is having an impact on their mental health.

The Diabetes Delivery Plan estimates that 41% of people living with diabetes (people living with diabetes) in Wales have poor psychological well-being.[xiv] People living with diabetes experience higher levels of psychological distress than people without diabetes.[xv] This is due to the additional stresses and pressure of diabetes, but also because there are specific psychological issues that only people living with diabetes experience.

People living with diabetes have double the risk of suicide or intentional self-injury compared with the general population. Further, most people with diabetes won't admit they are suicidal and will fail to inform healthcare professionals for fear of their response. Many suicide attempts might be mistaken for accidental hypoglycaemia or diabetic ketoacidosis. One study of 160 cases of insulin overdose leading to severe hypoglycaemia found that 90% were suicidal or parasuicidal and only 5% accidental. (Parasuicide is severe and deliberate self-harm with or without suicide intent that does not lead to death).[xvi]

In another study[4] of 550 children and young adults with type 1 diabetes, nearly 9% were identified as having some sort of suicidal ideation when screened with a questionnaire for depression and suicide. In fact, the World Health Organisation reported[5] that the number of suicide attempts is at least twenty times higher than the number of suicide deaths recorded.

Unmet psychological need significantly affects all areas of diabetes care; it increases psychological and physical risks to people living with diabetes and their families and adds substantial burden and cost to an already overstretched NHS. Links between increased psychological distress and worsening

diabetes self-management are also well established, with high diabetes distress predicting higher average blood glucose levels (as measured by HbA1c) in people with type 1 and type 2 diabetes.[xvii]

Diabetes UK Cymru continues to call for improved access to psychological services for people living with diabetes.

In June last year, Dr Rose Stewart, Consultant Clinical Psychologist and National Lead published her report "From Missing to Mainstream' A Values-based action plan for Diabetes Psychology in Wales.[xviii] Many diabetes services recognise the need for psychological support but often struggle to develop business cases and obtain funding for posts - this is often due to a lack of integration between physical and mental health services, which is a long-standing problem in the NHS.

Dr Rose Stewart's document sets out a framework for integrated specialist diabetes psychological care across Wales at all levels of need. The key recommendations of the document include the recruitment of a diabetes psychology workforce across Wales, specialist support for high-risk groups such as young adults, and integrating psychological thinking across all diabetes service developments.

Following a publication of a DUK Wales survey results of access to psychological support for people living with diabetes, conducted in August 2022, the CPG on Diabetes wrote to the Deputy Minister for Mental and Wellbeing, Lynne Neagle MS, on the 7th of December 2022. In response, the Deputy Minister in January noted:

*"The All-Wales Diabetes Implementation Group has commissioned the Cambridge Diabetes Education Programme for a few years, which also has modules on mental health in diabetes. We will consider with the clinical lead whether and how this can be further promoted across wider health care professional groups. In addition, the forthcoming Quality Statement for Diabetes will set out that health boards should provide tools and appropriate support to people with diabetes to help address the emotional and psychological impacts of living with this condition, and so I will expect to see how this is to be done reflected in health board plans."*[xix]

We look forward to reviewing the Quality Statement in June and continuing to work with Dr Rose Stewart on developing our calls for improved access to psychological support for people living with diabetes in Wales.

**Impact of Additional Factors, Prevention and Lifestyle**

The number of people diagnosed with diabetes continues to increase and is set to increase further as the rates of obesity continue to rise. There are currently 204,326 people registered as living with diabetes (Aged 17+) within Wales (Digital Insights & Variation Atlas 2022). This number will continue to rise with new people diagnosed with type 2 diabetes each year.

Recently the Wales Diabetes Remission Service Report was published by Catherine Washbrook-Davies, the All-Wales Nutrition & Dietetic Lead for Diabetes.

Her report highlights a programme implemented in Wales following the publication of the DiRECT study results. Work commenced by Dietetics departments within four university health boards in January 2020 to implement an All-Wales pilot for 90 patients to test the real-world implementation of delivering a Total Diet Replacement (TDR) based intervention to aid people with Type 2 diabetes to achieve remission through weight loss.

42 patients completed the 12-month intervention. For patients with two HbA1c results available at 12 months, remission was achieved in 62% of these, and 79% had improved their diabetes control

from baseline. The results indicate a major positive step for those for whom the diet was impactful; placing diabetes into remission can reduce the chances of developing lifelong complications, improve overall health and well-being and reduce pressures on other areas of life such as employment.

There are further positive benefits for the NHS—the immediate savings on administered medicine.

The total monthly cost for diabetes medication was approximately £1984.70, with a mean cost per patient of £22.30 (Range= 0- £118.62) and a mean number of 1.23 drugs per patient (Range= 0-4). This equates to a potential annual saving of £23,816 from the cohort who completed the programme. These savings are only for a 12-month period; therefore, if the 40 patients continue to maintain a lowered HbA1c level, these savings multiply year on year.

The report doesn't elaborate further on health economics; however, we know that delaying diabetes and keeping it in remission can prevent other life-impacting conditions, saving the NHS even further funding.

Funding for the continued delivery of the programme was provided through the All-Wales Diabetes Implementation Group (AWDIG), which is ceasing (funding to end in June) under the restructuring of the new NHS Executive. The Cross-Party Group on Diabetes has written to the Minister for Health and Social Services expressing support for continued funding of this programme. In her response, the Minister indicates a hopefully positive outcome for the programme, referencing the Quality Statement on Diabetes, which will be announced in June.[xx]

The All-Wales Diabetes Prevention Programme (AWDPP) was also launched this year, initially funded by AWDIG and now by the Welsh Government through Healthy Weight Healthy Wales. The programme is designed to target a standardised brief intervention with an embedded national evaluation approach to reduce the chances of those at risk of type 2 diabetes developing the condition.[xxi] The programme will offer those identified support to make changes to their diet, lifestyle and exercise to promote healthier choices and to be more physically active.

Although not as extensive as comparable programmes run in England[xxii], this is the first time a programme of this sort has been run in Wales and is now part of the Healthy Weight Healthy Wales Strategy to reduce obesity levels by 2030.[xxiii] The February update noted that 50% of the 3068 people identified using the AWDPP search template had taken up the programme.

The current food environment is the current major driver of the increased levels of obesity in Wales, increasing the health burdens associated with obesity.[xxiv] By allowing the continued increase in availability, accessibility, affordability, and marketing of foods high in saturated fats, trans fats, sugars and salt, which are highly processed, we are, in essence, on a non-stop train buffet, eating our way through to increased morbidity.

Our food environments are changing rapidly, especially for low and middle-income families with a comprehensive and heavily marketed availability of many products. These current food environments are the primary driver of increasing the burden of disease associated with obesity.[xxv] [xxvi]

Healthy diets are being undermined by marketing practices, with evidence being unequivocal; food marketing which children are exposed to alters their food preferences, choices, purchases and intake.[xxviixxviiixxix- Such] practices also affect their long-term physical health and emotional, mental and spiritual well-being.[xxxxxxi] These diets support life-long negative associations with foods that alter

their future choices of preferred food groups and their susceptibility to future marketing as an adult later in life.[xxxii,xxxiii]

Diabetes UK Cymru positively welcomed proposals in the Positive Food Environments and the Ban on Energy Drinks for those under 16s consultations. We have been informed that a statement on the developments of the proposals will be granted in June. As members of Obesity Alliance Cymru (OAC), we continue to call for reform for a more positive relationship with food and drink to reduce the levels of overconsumption of high-fat salt or sugar products.

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[v] Most latest data is only available to 2020.
[vi] https://www.diabetes.org.uk/guide-to-diabetes/complications/diabetic_ketoacidosis - Link to guides explaining DKA
[vii] https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/hba1c - Link to guides explaining blood glucose levels.
[viii] https://www.diabetes.org.uk/guide-to-diabetes/complications/cardiovascular_disease Link to guides on diabetes and heart disease.
[ix] Full breakdown of the respondents compared to the average demographics of people living with diabetes in Wales (NDA) and survey results can be provided to the Committee upon request.
[x] Information on the different types of technologies to support someone living with diabetes can be found on our website, accessed May 2023: https://www.diabetes.org.uk/guide-to-diabetes/diabetes-technology.
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[xix] Letter to the Deputy Minister from the CPG (Appendix 1) and the Deputy Minister's response (Appendix 2) are attached with consultation response.
[xx] The letter to the Minister of Health and Social Services, Eluned Morgan MS (Appendix 3) and the Minister's response (Appendix 4) are attached with this consultation response.
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DIABETES UK
DEALL DIABETES. BRWYDRO DIABETES.
KNOW DIABETES. FIGHT DIABETES.
CYMRU

**Jayne Bryant MS**

Welsh Parliament
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**17th of November 2022**

**Deputy Minister for Mental Health and Wellbeing,**
Lynne Neagle MS
Welsh Government
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CF99 1NA

**Dear Minister,**

I write on behalf of the Cross-Party Group on Diabetes. Following Diabetes UK Cymru's Missing to Mainstream Campaign launch which showcased Dr Rose Stewart's report , you will know that the charity has continued to call for increased access to dedicated psychological services for people living with diabetes.

Recently during the Summer of 2022, the charity wrote and collected survey data from people living with diabetes, asking them to share their experiences and thoughts about living with the condition.

During our last session of the CPG on diabetes, Diabetes UK Cymru shared its survey results (enclosed with this letter). Generally, it found that many respondents were frustrated with the lack of access to psychological support, the lack of appointments/GP contact, the lack of understanding by the public (especially in the workplace) and healthcare professionals of their condition and the offer of mental health support not being made or discussed.

Following our discussions at our last meeting, , the CPG would welcome an update from you as Deputy Minister for Mental Health and Wellbeing to understand the current landscape of access to mental health services for people living with diabetes

Considering the current workforce and budget issues and pressures that the NHS faces, members of the CPG, including Diabetes UK Cymru, expressed a view that a simple and cost-effective measure would be to improve access to general psychological support by improving understanding of diabetes amongst all healthcare professionals. Improved understanding and recognition would enable all healthcare professionals to identify issues, give support and signpost appropriately. The CPG would welcome a review of what steps could be taken to increase support and awareness of diabetes and its impact on mental health among healthcare professionals and the general public, so that people living with diabetes feel more supported and can access support when needed.

The CPG also expresses their thanks for your continued efforts and support, especially the day-to-day work that our NHS does to support people living with diabetes to live well.

We look forward to your response.
**Jayne Bryant MS**
Chair of the Cross-Party Group on Diabetes

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

Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref LN/00503/22

Jayne Bryant MS
Chair of the Cross Party Group on Diabetes
Senedd Cymru

Jayne.Bryant@senedd.wales

18 January 2023

Dear Jayne,

Thank you for your letter of 7 December on behalf of the Cross-Party Group about increased access to psychological support for people with diabetes. Many thanks also for enclosing the results of the summer survey which I read with interest.

I do understand that when faced with a diagnosis of diabetes, either Type 1 which is an autoimmune disease normally diagnosed in childhood, or Type 2 which is normally lifestyle-related and diagnosed in adulthood, people may well struggle to cope psychologically with what such a chronic, life-long condition means for their lives. Poor mental health may undermine effective self-care and medical management of diabetes; and in some cases, particularly in those dependent on insulin, diabetes can lead to more serious physical or mental health disorders.

This is a complex picture and people should be offered the right level of support at the right time to give them the tools to be resilient and to prevent and tackle concerning behaviours. A significant proportion of people with diabetes have poor psychological wellbeing and will require some degree of routine or specialist psychological support.

I agree that timely and appropriate psychological support would enable many people to cope better with their conditions and the *From Missing to Mainstream* report you mention includes a pyramid approach with improving psychological health and self-efficacy for all; a next tier of low level distress and minimal diabetes impact being addressed as part of routine care by non-specialists; a next tier addressed by non-psychology specialists with access to training, supervision and resources; a next tier requiring psychology professionals with training in diabetes and a highest level needing multiple professionals and case management.

The *From Missing to Mainstream* report makes an important contribution towards helping the NHS in Wales to take a stepped approach to deploying different interventions and resources according to the severity of the individual's needs. These recommendations are

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largely in line with the aims of the Together for Mental Health Delivery Plan which also sets out a range of levels of support as well as the Strategic Mental Health Workforce Plan for Health and Social Care which recognises that mental health and wellbeing is everyone's business.

I therefore note the Committee's helpful suggestion that improving understanding of diabetes amongst all healthcare professionals could be a simple and cost-effective way of supporting patients. The All-Wales Diabetes Implementation Group has commissioned the Cambridge Diabetes Education Programme for a few years which also has modules on mental health in diabetes. We will consider with the clinical lead whether and how this can be further promoted across wider health care professional groups. In addition, the forthcoming Quality Statement for Diabetes will set out that health boards should provide tools and appropriate support to people with diabetes to help address the emotional and psychological impacts of living with this condition and so I will expect to see how this is to be done reflected in health board plans.

Yours sincerely,

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

DIABETES UK
DEALL DIABETES. BRWYDRO DIABETES.
KNOW DIABETES. FIGHT DIABETES.
CYMRU

Jayne Bryant MS
Chair of the CPG on Diabetes
Senedd Cymru
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**February 2023**

**Minister for Health and Social Services,**
Eluned Morgan MS
Welsh Government
5th Floor
Tŷ Hywel
Cardiff Bay
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**Dear Minister,**

I write on behalf of the Cross-Party Group on Diabetes; in our first meeting of the year, we welcomed a presentation by Catherine Washbrook-Davies, the All Wales Nutrition & Dietetic Lead for Diabetes (Adult) & All Wales Diabetes Prevention Programme (AWDPP) on the All-Wales Type 2 Diabetes Remission Service.

With interest, members learnt of the very welcoming achievements of the Service funded by AWDIG from January 2020 – March 2022 to test total diet replacement-based intervention to aid people with type 2 diabetes to achieve remission through Weight loss.[i]

The report highlights several beneficial results for both the people living with diabetes, who achieved weight loss and the Welsh NHS, potentially saving and continues to save £23,816 annually just on diabetes medication alone. The long-term impact that programmes such as these can have on the NHS to prevent diagnosis of type 2 diabetes and place type 2 diabetes into remission is yet to be assessed and calculated. However, it can be determined that such results could reduce pressure on the NHS and deliver further cost savings as people improve their health.

With the business case for future funding under review, the CPG on Diabetes would like to express its support for expanding the Service. Members felt that the results of the Service spoke for itself and provided a real opportunity to improve the health of those living with type 2 diabetes, reducing their health risk and associated complications and supporting the NHS.

I hope that you agree, and I look forward to your response.

**Warm regards,**

Jayne Bryant MS

Chair of the Cross-Party Group on Diabetes

[i] Report attached with this letter.

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

Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref EM/00969/23

Jayne Bryant MS
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17 April 2023

Dear Jayne,

Thank you for your letter of 27 March on behalf of the Cross-Party Group on Diabetes regarding the All-Wales Type 2 Diabetes Remission Service.

I welcome sight of the enclosed report and the Group's support for the introduction of this intervention. With the predicted rise in type 2 diabetes and the large personal and societal impact of diabetes prevalence, it is vital the NHS adapts to prevent type 2 diabetes, and where possible support people to achieve remission.

In June I expect to publish the Quality Statement for Diabetes, which includes commitments for the continued development of diabetes remission services. I hope to say more about this to the Senedd on the day of publication.

Thank you for writing to me on this matter.

Yours sincerely,

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

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# Health and Social Care Committee:
## Supporting People with Long Term Conditions

# Consultation response from the Royal College of Paediatrics and Child Health (RCPCH)

**May 2023**

## About the RCPCH and our response

The RCPCH works to transform child health through knowledge, innovation and expertise. We have over 500 members in Wales, 14,000 across the UK and over 17,000 worldwide. The RCPCH is responsible for training and examining paediatricians. We also advocate on behalf of members, represent their views and draw upon their expertise to inform policy development and the maintenance of professional standards.

We agree with the Committee that issues around chronic conditions are wide ranging and complex. With this in mind, we will seek to identify a small number of key considerations that we hope will help inform the Committee's thinking and understanding of the issues around long term conditions in children and young people, rather than take an in-depth look at specific conditions and care pathways. We'll align these as far as possible to the broad areas identified by the Committee on the consultation page.

We would be pleased to elaborate on this response in an oral evidence session, should the Committee have further questions or wish to hear more about supporting children and young people with long term conditions. For further information please contact Lisa Roberts, Policy and Public Affairs Officer (Wales) at the RCPCH at lisa.roberts@rcpch.ac.uk.

# Key considerations

**Prioritising children and young people is essential to ensure that services can meet future demand.**

In years gone by, the majority of deaths in children were in those acutely unwell from infectious disease with no underlying morbidities. The number of children with a single long-term health condition such as asthma, diabetes, inflammatory bowel disease, eczema and epilepsy has increased significantly in more recent years. Now, between 60% and 70% of children who die in the UK have a long term condition[1].

There is therefore a strong case for prioritising children and young people in formulating policy, resourcing and services around long term illness[2], including the long term implications for health services. Healthy children are more likely to become healthy adults. Poor health outcomes in childhood are likely to progress into adulthood. If we take mental health as an example, the Mental Health Foundation report that 50% of mental health problems are established by age 14 and 75% by age 24[3]. Meanwhile, Young Minds note that One-third of mental health problems in adulthood are directly connected to an adverse childhood experience and that adults who experienced four or more adversities in their childhood are four times more likely to have low levels of mental wellbeing and life satisfaction[4].

The Welsh Government recognises the strength of the case for prioritising children and young people and have set this out in at least two key documents. It's long term strategy for health and social care, A Healthier Wales, noted the case for prioritising children and young people, drawing on evidence from an earlier Parliamentary Review[5]. The Welsh Government's programme for transforming and modernising planned care and reducing waiting lists in Wales builds on this, noting that "waiting times for children must be considered differently to waiting times for an adult, as the illness will represent a higher proportion of a child's whole life and potentially have permanent long term impact on growth and development"[6]. The document also

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[1] Royal College of Paediatrics and Child Health (2020), 'Child with Single Long Term Condition' in *Paediatrics 2020: Forecasting the Future*. Available at: https://paediatrics2040.rcpch.ac.uk/our-evidence/models-of-care/future/#page-section-9. Accessed May 2023.

[2] For a discussion of some aspects of this case see, for example, Lignou S, Wolfe I Healthcare prioritisation and inequitable inequalities: why a child health perspective should be incorporated into the current NHS guidance. *Archives of Disease in Childhood* Published Online First: 19 May 2023. Available at: https://adc.bmj.com/content/early/2023/05/18/archdischild-2023-325634. Accessed May 2023.

[3] Mental Health Foundation *Children and Young People Statistics*, available at: https://www.mentalhealth.org.uk/explore-mental-health/statistics/children-young-people-statistics#:~:text=50%25%20of%20mental%20health%20problems,and%2075%25%20by%20age%2024. Accessed May 2023.

[4] Young Minds *Mental Health Statistics*, available at https://www.youngminds.org.uk/about-us/media-centre/mental-health-statistics/. Accessed May 2023.

[5] See Welsh Government (2018) A Healthier Wales, p18. Available at: https://www.gov.wales/healthier-wales-long-term-plan-health-and-social-care. Accessed May 2023.

[6] Welsh Government *Our programme for transforming and modernising planned care and reducing waiting lists in Wales* (2022), p22. Available at: https://www.gov.wales/sites/default/files/publications/2022-04/our-

makes reference to prioritising or recognising particular needs of children and young people in terms of dentistry[7], mental health[8], elective care[9] and diagnosis[10]. Given the impact that living with a chronic illness during childhood has on school attendance, health in adulthood and on a person's lifetime opportunities, we strongly believe that prioritising children and young people is key to ensuring that services can meet future demand.

We would encourage the Committee to consider hearing directly from children and families living with long term conditions and to look at resources we have produced with our engagement network, called RCPCH &Us. This includes, as an example, specific work with children and young people on their experiences of epilepsy care[11].

Underpinning any commitment to prioritising children and young people's health must be a properly resourced child health workforce with the appropriate capacity to manage demand and ensure timely access to paediatric services. Over the past two years we have seen significant increases in waiting lists to access general paediatric services and in particular in waits of over 36 weeks[12]. We would like to see delivery and implementation of existing workforce plans in Wales, which must be properly resourced and funded; and enable proactive planning and modelling based on robust workforce data, in line with commitments made in 'Healthier Wales: Our Workforce Strategy for Health and Social Care' and 'Our Programme for Transforming and Modernising Planned Care and Reducing Waiting Lists in Wales'.

Finally, we must also ensure that services work together. This is not only across education and social care but also between paediatric and adult care to ensure the needs of adolescents and young adults are met. This population consistently lags behind in improvements in morbidity and mortality and attracts the least funding yet is the time when health related knowledge and behaviours are typically set. It is essential that services for this population acknowledge key neurodevelopmental issues and reduced life experience and are in line with principles set out by the Welsh Government[13]. We elaborate on this point and its importance in terms of managing chronic conditions in Paediatrics 2040:

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programme-for-transforming--and-modernising-planned-care-and-reducing-waiting-lists-in-wales.pdf. Accessed May 2023.

[7] Welsh Government (2022), p9.

[8] Welsh Government (2022), p10.

[9] Welsh Government (2022), p23

[10] Welsh Government (2022), p2.

[11] Royal College of Paediatrics and Child Health (2018), *Epilepsy12 &Us - voices from the RCPCH &Us network*. Available at: https://www.rcpch.ac.uk/resources/epilepsy12-us-voices-rcpch-us-network. Accessed May 2023.

[12] See Stats Wales, *Patient pathways waiting to start treatment by month, grouped weeks and treatment function, January 2021 onwards*. Available at: https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Referral-to-Treatment/patientpathwayswaitingtostarttreatment-by-month-groupedweeks-treatmentfunction. Accessed May 2023.

[13] See Welsh Government (2022), *Transition and handover from children's to adult health services*. Available at: https://www.gov.wales/transition-and-handover-childrens-adult-health-services. Accessed May 2023.

"Getting health services right for adolescents is of critical importance, as it is during this period that many long-term health conditions emerge, and associated behaviours can have most impact. Offering developmentally appropriate care with the ability to adapt to changing biopsychosocial profiles, and addressing physical, sexual, social and mental health needs in consultations, will be important. Dedicated young people's clinics, specific ward areas, the presence of youth workers and a multidisciplinary approach are all considerations, as well as integration with primary care and adult physicians. The RCP has a toolkit which sets out some broad categories and reminds us to consider information sharing, professional responsibilities and confidentiality.[14]"

**Inequalities and the impact of the cost of living crisis**

Our position statement on **Child health inequalities driven by child poverty in the UK** and the **Mind the Gap** report produced by the NHS Confederation and a number of Medical Royal Colleges and third sector groups in Wales, clearly set out the evidence on links between poverty, inequalities and poor health outcomes. The former includes specific consideration of long term conditions, noting that:

- Children living in poverty are significantly more likely to suffer from acute and long-term illness. They are significantly more likely to require hospital admission and were 72% more likely than other children to be diagnosed with a long-term illness.
- In Wales, the gap between obesity prevalence in the most and least income deprived quintiles has increased from 5.9% in 2017/18 to 6.9% in 2018/19.
- Children living in poverty are more likely to be at risk of tooth decay, in prevalence and severity. In Wales, 42.2% of five-year olds in the most income deprived areas have tooth decay, compared to just 22.3% in the least income deprived areas.
- Children living in the poorest 20% of households in the UK are four times more likely to develop a mental disorder as those from the wealthiest 20%.[15]

Another example would be asthma. Our State of Child Health report notes that:

- **Asthma is the most common long term condition among children and young people in the UK**, with 1.1 million children currently receiving asthma treatment. It continues to be among the top 10 causes of emergency hospital admission for children and young people in the UK.
- **The UK has among the highest mortality rates in Europe** for children and young people with the underlying cause of asthma.

[14] Royal College of Paediatrics and Child Health (2020), *Paediatrics 2040: Forecasting the Future*. Available at: https://paediatrics2040.rcpch.ac.uk/our-evidence/models-of-care/future/. Accessed May 2023.
[15] Royal College of Paediatrics and Child Health (RCPCH), 2022. *Child health inequalities driven by child poverty in the UK - position statement.* Available at: https://www.rcpch.ac.uk/resources/child-health-inequalities-position-statement. Accessed May 2023.

- **Emergency admissions, and deaths, related to asthma are largely preventable** with improved management and early intervention.
- **Emergency admissions for asthma are strongly associated with deprivation**. Children and young people living in deprived areas are more likely to be exposed to higher levels of tobacco smoke and environmental pollution, which may contribute to this. If emergency admission rates for all children and young people were at the levels experienced by the least deprived group, this could save the NHS £8.5 million per year in England alone.[16]

Although this final point looks at England specifically, the principle is relevant in Wales.

We therefore welcome the announcement that there will be a refreshed and updated child poverty strategy for Wales, which we hope will be prioritised and expediated; and we would encourage the Welsh Government to consider child health outcomes and child health inequalities as part of that work. The strategy should provide national targets to reduce child poverty rates, with clear accountability across Government. We would also encourage the Welsh Government to review and expand the Children and Young People Plan so that future iterations form a comprehensive cross-departmental child health and wellbeing strategy that will address health inequalities and the impact of child poverty; and outline the role each department has in contributing to solutions.

Among the many areas in which long term conditions and child health inequalities intersect is in school attendance. With this in mind, we Welcome the Welsh Government's Whole School Approach to mental health and the Healthy Schools scheme delivered by Public Health Wales. We urge the Welsh Government to ensure these programmes are adequately resourced and delivered at pace with robust evaluation to capture and roll out learning. A wider 'whole school approach' to health could incorporate physical as well as mental health and we note that organisations working with or on behalf of children and young people with diabetes[17], arthritis[18], Coeliac disease[19], epilepsy[20] and other conditions as well as the *Health Conditions in School Alliance* have produced resources that may be of use to education professionals in considering how to support learners with chronic conditions.

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[16] Royal College of Paediatrics and Child Health *State of Child Health* available at: https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/asthma/. Accessed May 2023.
[17] See, for example, Diabetes UK, *Diabetes in School*. Available at: https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools.
[18] See, for example, Versus Arthritis, *Supporting a young person with arthritis at school*. Available at: https://www.versusarthritis.org/media/24208/supporting-a-young-person-information-booklet-oct2021.pdf
[19] See, for example, Coeliac UK, *Coeliac disease at school*. Available at: https://www.coeliac.org.uk/information-and-support/living-gluten-free/kids-teens-and-young-adults/coeliac-disease-at-school/. Accessed May 2023.
[20] See, for example, Young Epilepsy, *Attendance*. Available at: https://www.youngepilepsy.org.uk/guide-schools-epilepsys-impact-learning/guide-schools-attendance; and *Exams and Coursework*. Available at: https://www.youngepilepsy.org.uk/guide-schools-epilepsys-impact-learning/guide-schools-exams-coursework

**Action to improve prevention and early intervention.**

Action to prevent children and young people from developing chronic or long term conditions is absolutely vital if we are to reduce the numbers of children and young people being ill, missing school or requiring hospital treatment – and if we are to safeguard services in the future.

We have welcomed the Welsh Government's Healthy Weight Healthy Wales programme, which must be delivered in full and at pace, given the extremely concerning data on childhood obesity and the inequalities underpinning those numbers revealed by the Child Measurement Programme for Wales. Healthy Weight Healthy Wales includes a commitment to expanding that programme[21] so that we have data points other than at reception age and are better able to understand children and young people's weight throughout their school careers. This work must be delivered with urgency. We have also called for full and swift implementation of the policy and legislative package around the healthy food environment consulted upon by the Welsh Government last year as part of its HWHW commitments[22].

HWHW also includes a range of commitments and interventions to increase physical activity and reduce sedentary behaviour and lifestyles in children and young people, which we welcome both as a measure to reduce childhood obesity and to improve children's health more broadly by supporting a healthier lifestyle which can contribute to preventing long term disease. The Welsh Government consulted last year on a new framework for social prescribing[23] in Wales and we hope that when the updated framework is published, that it will have a far greater focus on children and young people in general and in particular greater consideration as to how social prescribing can interact with community sport and leisure facilities and youth clubs to encourage physical activity; as well as interact with other relevant Welsh Government initiatives, legislation and programmes such as the ALN framework, the healthy schools programme and the Whole School Approach. The social prescribing framework could also be helpful in developing self-management tools specifically for children and young people living with long term illness: experience from members suggests that self-management support can often be adult-focused.

We have also been supportive of the Welsh Government's commitments around tobacco control and its strategy, A Smoke Free Wales. In particular we have welcomed the ambition for Wales to be smoke-free Wales by 2030, the commitment

[21] See Welsh Government (2022) *Healthy Weight Healthy Wales Moving Ahead in 2022- 2024,* National Priority Area 7. Available at: https://www.gov.wales/sites/default/files/publications/2022-03/healthy-weight-healthy-wales-2022-to-2024-delivery-plan_0.pdf. Accessed May 2023.
[22] See Royal College of Paediatrics and Child Health (2022) *Healthy Food Environment (Wales) – consultation response*. Available at: https://www.rcpch.ac.uk/resources/healthy-food-environment-wales-consultation-response. Accessed May 2023.
[23] See Welsh Government, *Developing a national framework for social prescribing*. Available at: https://www.gov.wales/developing-national-framework-social-prescribing. Accessed May 2023.

to taking further steps to protect people from the harms of second-hand smoke and the focus on children and young people[24].

We have previously noted the importance of prevention and early intervention around mental health and neurodiversity and the need to ensure comprehensive rollout of programmes such as the NYTH/NEST approach and the Whole School Approach.

Finally, we have also welcomed a Welsh Government White Paper on legislation for better air quality in Wales.

Taken together, these strategies and policies could have a significant impact on preventing long term illness in children and young people. We are also pleased to see that preventative initiatives in Wales take a whole family approach (for example, we are aware that Public Health Wales are piloting children and families projects as part of Healthy Weight Healthy Wales; and understand that work around preventing Adverse Childhood Experiences or ACEs has a focus on the wider family as well as the individual child). Taking a whole family approach to supporting healthy choices and preventing generational cycles of behaviours detrimental to health could be beneficial in a range of other preventative and self-management approaches to long term illness in children, such as managing chronic pain and fatigue.

[24] See Royal College of Paediatrics and Child Health (2022), *Tobacco control strategy and delivery plan (Wales) consultation response*. Available at: https://www.rcpch.ac.uk/resources/tobacco-control-strategy-delivery-plan-wales-consultation-response. Accessed May 2023.

# Agenda Item 4

ROYAL PHARMACEUTICAL SOCIETY
Wales Cymru

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

**Consultation: Supporting people with chronic conditions**

Dear Russell,

Thank you for this further opportunity to support the committee's work on this important topic.

We know that medicines are the most common intervention in the management of chronic conditions. For patients they can be life-prolonging and life-saving. However they can also cause harm and lead to unnecessary wastage if used incorrectly.

As the experts in the safe and effective use of medicines within the health service, pharmacists must play a central role in supporting people with chronic conditions to get the best outcomes from their medicines. Consistent use of pharmacists' expertise will also help reduce adverse reactions to medicines, minimise avoidable harm and un-planned admissions to hospital.

The contribution below goes into greater detail on how pharmacist are already supporting people with chronic conditions and how their skills can be utilised further - touching on some of the broad areas you have highlighted in your introduction to the consultation.

We hope the information is helpful. Please do get back in touch if any further information would be helpful.

Kind regards

Cheryl Way
Chair, the Royal Pharmaceutical Society's Welsh Pharmacy Board

**Prevention and self-management**

The Self Care Forum advocates for an approach that encompasses 'four pillars of self care'[1].The pillars comprise of lifelong learning, empowerment, information and local and national campaigns.

The table below illustrates how pharmacy teams are well placed to support individuals at each point of this engagement model.

| | |
|---|---|
| Lifelong learning | Every week thousands of people visit community pharmacies in Wales for medicines and health advice. The often-informal nature of the contact with a pharmacist and the wider team enables them to provide opportunistic healthy living education, advice and support for people at every stage of life. |
| Empowerment | The accessibility of the community pharmacy network on the high street, supermarkets and rural communities provides a gateway to health and medicines advice from a healthcare professional without the need for an appointment. Pharmacists can offer reassurance and empower people to take greater control of their own health and wellbeing. |
| Information | As a trusted healthcare profession, pharmacists provide a reliable and confidential source of health and medicines information. The pharmacy team can also ensure that individuals are signposted to trusted resources and groups for further information about their physical and mental health.<br><br>Self-assessment tools on how to reduce risk could also be used with individuals to assess and understand their relative risk of developing a chronic condition.<br><br>Obesity and smoking, for example, are linked with many chronic conditions. Pharmacists can advise on reducing risk by providing information on positive lifestyle choices, supporting positive behavioural change, information on self-care and providing services such as smoking cessation programmes. |
| Local and national campaigns | An essential service that a community pharmacy provides is the promotion of healthy lifestyles and wellbeing. One way this is undertaken is via public health campaigns. Each community pharmacy in Wales is contracted to undertake 6 public health campaigns every year. Multidisciplinary national and local campaigns could provide a real opportunity for consistent messages to be delivered to all individuals. |

**Timely Detection**

When an individual first starts to experience symptoms of ill-health, they may initially attempt to self-manage. People will often seek advice from a community pharmacy and this is an ideal opportunity for the pharmacist to detect early warning signs of what could become a chronic conditions.

Timely detection and referral can make a significant difference to people's quality of life, particularly at the early stages of a chronic condition such as rheumatoid arthritis and dementia. Pharmacists see people regularly and are able to detect signs and symptoms of some chronic conditions on an opportunistic basis e.g dementia, arthritis and respiratory conditions.

[1] https://www.selfcareforum.org/2015/03/30/self-care-forum-manifesto/

However, the current lack of a formal referral process from community pharmacy leads to delays in access to treatment for the patient. Despite being the most accessible health professional group with such regular interaction with patients, when people present at a pharmacy with symptoms of a chronic condition that requires referral, the pharmacist has few options other than suggests they visit their GP. This will be the case even though the pharmacist may have already recognised that the patient would benefit from quick access to another health or social care professional.

The lack of a formalised referral system leads to patients always having to take an extra step themselves before they get the care they need, rather than it being facilitated for them by the health service. Furthermore, if a person does not follow up on their pharmacist's advice to contact their GP, it risks that individual being lost to the health service and not receiving a diagnosis and support they need for a chronic condition.

To streamline referral processes, we recommend that formal referral protocols/pathways should be developed for pharmacy teams to make direct referrals to other services. Their aim should be to remove burden from patients themselves and allow them to move through the health system more rapidly and efficiently. These protocols/pathways should be developed with input from across multidisciplinary team and patients' representatives so that they are tailored to what patients need and expect.

Finally, more opportunities for simple testing for chronic conditions should also be explored as part of preventative approaches to healthcare (e.g. testing blood sugar levels for diabetes or blood pressure measurements to prevent strokes). Timely detection with appropriate information and support and simple lifestyle changes could prevent significant medical interventions and hospital admissions in the longer term.

**Treatment**

Once an individual has been given a diagnosis of a chronic condition, ongoing support must be provided by an appropriate skilled multidisciplinary team. As part of this approach, pharmacists should take overall responsibility for the medicines management aspect of this care.

When prescribed and used effectively medicines have the potential to significantly improve quality of life and improve outcomes for individuals with a chronic conditions. By focusing on a holistic approach to pharmaceutical care, pharmacists can support individuals to maintain good health and wellbeing and avoid complications of their existing chronic condition, as well as working to prevent the development of further chronic conditions.

Pharmacists across all sectors in Wales are already supporting patients with chronic through various models of care. However, a consistent approach is required.

Such an approach to pharmacy's role in chronic disease management has been identified within the profession's 2030 vision *Pharmacy: Delivering a Healthier Wales*.[2] The model below illustrates the desired model for each sector of pharmacy to take its appropriate role in supporting people with chronic conditions at every stage:

[2] https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Policy/Pharmacy%20Vision%20English.pdf?ver=2019-05-21-152234-477

| | |
|---|---|
| Community Pharmacy | All patients that have stable, well controlled chronic condition will be monitored and managed in their community pharmacy. This will ensure ease of access for patients to their regular medicines, with appropriate, tailored timescales between consultations depending on current stability of their health condition. |
| Primary Care | Pharmacy teams at cluster or general practice level, integrated into multidisciplinary models, will provide medicines interventions for patients who are newly diagnosed or who have unstable or worsening chronic condition(s). |
| Hospital | Only those patients who require urgent, intensive or highly specialist care will require access to specialist pharmacists and their teams within the hospital setting. These specialist pharmacists will also be enabled to input into their patients' care at a local level. |

Across all sectors, the growing prescribing capacity with pharmacy will be a key enabler to develop the profession's role in chronic conditions management to grow.

**Multimorbidity**

The committee is right to identify the need to support patients diagnosed with multiple chronic conditions. Such patients will typically need complex medication regimens with more intensive support from pharmacists. It is recognised that the impact of co-morbidity is profound and multi-faceted. Patients with several chronic conditions typically have poorer quality of life, poorer clinical outcomes, longer hospital stays and more postoperative complications, and are more costly to health services.

Using multiple medicines for multiple conditions can become problematic (polypharmacy) where medications are prescribed inappropriately, or where the intended benefit of the medication is outweighed by the risk. The more medicines an individual is prescribed, the greater the risk of drug interactions and adverse drug reactions, as well as impaired adherence to medication and a reduced quality of life.

As the number of individuals with co-morbidities become more prevalent, the challenges associated with prescribing the right medicines and supporting patients to use them effectively should not be underestimated. This increase in complexity means that prescribers have the challenge of dealing with potential interactions between medicines prescribed for different conditions.

Managing polypharmacy is where the expertise of the pharmacist is essential as part of multidisciplinary approaches to care. The in-depth pharmacology and medicines expertise of the pharmacist is essential when considering the optimal medication regimen for an individual with co-morbidities. Following condition specific guidelines may not always be the most appropriate course of action for the individual. Pharmacists must therefore play a leading role in the optimisation of medication regimens for patients with chronic conditions. This will ensure appropriate use of medicines, stopping inappropriate medicines as well as considering opportunities for lifestyle changes and non-medical therapies.

**Y Pwyllgor Iechyd a Gofal Cymdeithasol**
–
**Health and Social Care Committee**

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Rt Hon David TC Davies MP
Secretary of State for Wales

23 January 2024

Dear David

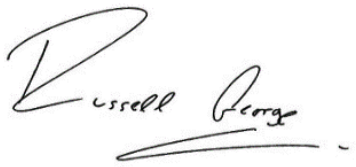
The Committee is currently in the process of preparing its report on the Welsh Government's draft budget 2024-25. As part of that work, we held an oral evidence session on 17 January with the Minister for Health and Social Services, Eluned Morgan MS.

During that session, in discussion on the junior doctor strikes and the various pay offers that have been made to doctors across the UK, the Minister told us that she has been unable to get clarity from the UK government about the source of the 6 per cent uplift offered to junior doctors in England. This is significant because, as you will be aware, if the uplift is to be funded from a central budget, Wales will be entitled to additional consequential funding, whereas if it is to be funded from within the existing health budget for England, there will be no such consequential payment.

This is clearly an important issue, and one that needs confirming urgently, not least so that the Welsh Government is able to plan effectively.

The Committee would be grateful if you would look into this matter and provide us with some clarity. We must lay our report on the draft budget by 5 February. We would, therefore, appreciate a response in advance of that.

Yours sincerely



Russell George MS
Chair, Health and Social Care Committee

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

# Agenda Item 5.2

UK Government
Llywodraeth y DU

**Rt Hon David TC Davies MP**
Secretary of State for Wales
Ysgrifennydd Gwladol Cymru

**T:** 0292 092 4216
**E:** Correspondence@ukgovwales.gov.uk

Ref: 004SOS24

**Russell George MS**
Chair, Health and Social Care Committee
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN
Email: SeneddHealth@senedd.wales

5th February 2024

Dear Russell,

**Re: Junior Doctor Pay Uplift**

Thank you for your letter regarding junior doctor pay and the Welsh Government's draft budget for 2024/25.

The junior doctor pay uplift in England is being funded from within existing DHSC budgets. The Barnett formula has been applied to all changes to DHSC budgets. Any additional funding for DHSC this year will be confirmed through the Supplementary Estimates process, at which point the Welsh Government will receive funding through the Barnett formula in the usual way.

It is for the Welsh Government to decide how to allocate their funding in devolved areas, and they are well funded to deliver all their devolved responsibilities receiving around 20% more funding per person than equivalent UK Government spending in England. Barnett

HM Treasury are in regular contact with the Welsh Treasury to provide the best information available to help them plan in advance of Supplementary Estimates numbers being finalised.

Yours sincerely,

David T.C. Davies

**Rt Hon David TC Davies MP**
Secretary of State for Wales
Ysgrifennydd Gwladol Cymru

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



Llywodraeth Cymru
Welsh Government

Russell George MS
Chair, Health and Social Care Committee
SeneddHealth@senedd.wales

Mark Isherwood MS
Chair, Public Accounts and Public Administration Committee
SeneddPAPA@senedd.wales

6 February 2024

Dear Russell and Mark,

I wrote to you last November and agreed to provide an update on the oversight and escalation framework. As you are aware I reissued the framework on the 22 January 2024 and this can be found at: Oversight and Escalation Framework.

The previous escalation and intervention framework was introduced in 2014 following previous PAC recommendations. Since its introduction the tripartite partners - Welsh Government, Healthcare Inspectorate Wales and Audit Wales, together with health organisations, have learnt lessons through the delivery and operationalisation of the arrangements. Many things have changed because of this learning. There is some evidence that the current arrangements show some evidence of improvement amongst those health boards that have been escalated.

Considerable work has been undertaken on this Framework and the refreshed version builds upon the engagement and feedback that has been received over the last few years through workshops, questionnaires and discussions with NHS organisations. The review process included an assessment of the processes in operation in England and Scotland and has identified a number of areas that needed to be addressed including:

- The current escalation and intervention framework is in need of a refresh.
- The criteria for de-escalation is not always clearly defined. There needs to be a clear framework and financial indicators that determine where in the framework each organisation should be and what triggers de-escalation.
- Clearer levels of support and action need to be set for each level of the framework.
- The current system is too focused on acute health services – not ‘whole system’.
- Insufficient focus on diagnosing ‘root cause’ of difficulties (to ensure most appropriate/effective response is adopted).
- Can be interpreted as punitive rather than supportive (‘done to’ Boards rather than working with them).
- No option for Boards to proactively seek support.
- Quality of/availability of appropriate support packages (resourcing of relevant skills).

NHS organisations and tripartite participants have had opportunity to comment on draft versions of the revised framework and where appropriate their comments and suggestions have been incorporated into the final document.

The refreshed version builds heavily upon the learning and experiences of the health boards that have been in special measures. The oversight and escalation framework sets out the statutory environment within which the framework operates including the links to the planning and performance frameworks. It sets out the process through which the Welsh Government gains assurance on NHS bodies and how the escalation and de-escalation process works. The framework sets out the domains (based upon the quality standards) against which each organisation is assessed and challenged. The framework also includes a new escalation level – "level 2". This is intended to allow Welsh Government and the NHS Executive to work with the health board in a proactive manner to prevent formal escalation.

I hope that this update is helpful and please let me know if you require any further information or briefing on these matters.

Yours sincerely,

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

Coleg Nyrsio Brenhinol Cymru
Royal College of Nursing Wales

**Royal College of Nursing**
Ty Maeth
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**Helen Whyley, RN, MA**
Director, RCN Wales

Telephone [redacted]
Email [redacted]

31st January 2024

Russell George MS
Chair of Senedd Health and Social Care Committee

Emailed to: russell.george@senedd.cymru
cc: Members of the Health & Social Care Committee

Dear Russell,

I write to you to ask the Senedd's Health and Social Care Committee to **scrutinise the recent decision made by the Minister for Health and Social Services to introduce the role of Registered Nursing Associate in Wales.**

On 19th January, the Minister for Health and Social Services announced her intention to introduce a regulated band 4 nursing role for the NHS in Wales, subject to the necessary UK legislative amendments. The Minister wrote in her statement that she will *"undertake public consultation on developing the parameters of practice for the new role in Wales"* later in the year, and described the change as being the *"biggest and most impactful review of nursing in Wales since the introduction of the graduate nurse in 2004."*[1]

RCN Wales welcomes the Minister's statement that she will open a public consultation on the scope of the role but believes that the public also needs to be consulted on the question of whether the nursing associate role should be introduced into Wales at all. The Minister has taken this decision before sharing publicly the findings and recommendations of the work undertaken to gather evidence and stakeholder views. RCN Wales looks forward to scrutinising this report when it is published. The Minister has expressed her commitment to the Royal College of Nursing towards continued collaborative working between her officials and RCN Wales as the work to introduce this role unfolds. RCN Wales welcomes this.

Answers to key questions surrounding the policy have not yet been provided by the Welsh Government. RCN Wales believes that the Health and Social Care Committee should scrutinise the Welsh Government's policy to ensure answers to the following questions:

Continued…..

[1] Written Statement: Policy Intent for introduction of a regulated band 4 nursing role for the NHS in Wales, subject to the necessary UK legislative amendments (19 January 2024) | GOV.WALES

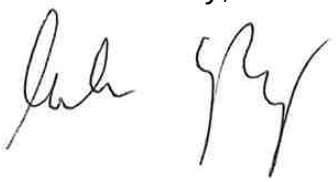
- **What is the financial impact of the proposed changes she has outlined with the introduction of the registered nursing associate role in Wales?**
- **How much government funding has been allocated for this introduction?**
- **What are the financial implications for both the funding of the education of the Trainee Nursing Associate and the individual health boards costs with the implementation of this policy?**
- **Can the Welsh Government provide assurance that government funding will not be removed from the HEIW financial allocation to degree level pre-registration nursing to fund this new initiative?**

In addition, RCN Wales asks the Health and Social Care Committee to make a recommendation as part of its safe staffing inquiry to include appropriate use of nursing associates in the statutory guidance.

Along with this letter, I attach a briefing for the attention of the Health and Social Care Committee outlining some of the concerns that RCN Wales has surrounding the decision to introduce the role of the nursing associate in Wales.

I look forward to further discussion of this matter.

Yours sincerely,



**HELEN WHYLEY, RN, MA**
**DIRECTOR, RCN WALES**

Coleg Nyrsio Brenhinol Cymru
Royal College of Nursing Wales

# RCN Wales concerns regarding the planned introduction of nursing associates in NHS Wales

*A briefing for the Senedd Health and Social Care Committee*

Key action point:

**RCN Wales calls for Health and Social Care Committee scrutiny on the Welsh Government's new policy to introduce nursing associates in NHS Wales**

On the 18th of December, the Minister for Health and Social Services wrote to RCN Wales Director, Helen Whyley, giving her *"formal notification of the new Welsh policy position and my intention to trigger the next important work stream to prepare for the potential introduction of a regulated band 4 nursing role in Wales, pending the necessary legislative amendments."*

Subsequently, on 19 January 2024, the Minister for Health and Social Service issued a written statement officially announcing her intention to introduce the Nursing Associate role into Wales, subject to the necessary UK legislative amendments.

Registered nursing associates have been part of the Nursing and Midwifery Council (NMC) register in England since 2018.[1]

The NMC's powers and duties are set out in its governing legislation, which is the Nursing and Midwifery Order 2001. Amendments to the Nursing and Midwifery Order can be made using the powers under Section 60 of the Health Act 1991.[2] The new policy was introduced in England in the form of The Nursing and Midwifery (Amendment) Order 2018.[3]

With the regulation of professional bodies being a reserved matter, the Minister for Health and Social Services is requesting that the UK legislation be amended to allow the NMC register to include nursing associates in Wales.[4]

RCN Wales is calling on the Committee to scrutinise this decision by the Welsh Government to introduce the role of the nursing associate in Wales.

[1] RCN position statement on the role and scope of practice of the Nursing Associate | Royal College of Nursing
[2] Rona-consultation.pdf (publishing.service.gov.uk)
[3] The Nursing and Midwifery (Amendment) Order 2018 (legislation.gov.uk)
[4] Backlash over plans for regulated band 4 nursing role in Wales | Nursing in Practice

Coleg Nyrsio Brenhinol Cymru
Royal College of Nursing Wales

Key points:

1. The Royal of College of Nursing believes that the introduction of nursing associates could be a positive addition to the current workforce, provided that it is **fully funded** and that it is **in addition to the current workforce**.

2. The Royal College of Nursing is clear that, under no circumstances can the replacement of registered nurses by nursing associates be allowed, as this would seriously increase the risks to **patient safety**.

3. The Royal College of Nursing believes that **health care support workers** (Agenda for Change bands 1-4) are an essential part of the nursing workforce. Nursing associates should join the nursing team as an addition rather than as a replacement.

4. The Royal College of Nursing requests more information on the planned funding from the Welsh Government for the introduction of the nursing associates role.

## Suggested questions for the Minister for Health and Social Services:

**1.** What will be the **financial impact** of this new policy?

**2.** How much government **funding** has been allocated for this introduction?

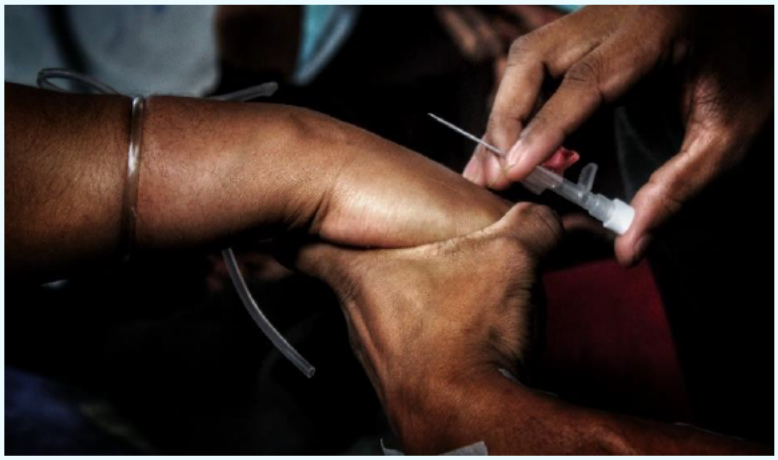
**3.** What are the financial implications for both the funding of the education of the **Trainee Nursing Associate** and the individual health boards costs with the implementation of this policy?

**4.** Can the Minister for Health and Social Services give a clear assurance that government funding will not be removed from the HEIW financial allocation to degree level pre-registration nursing to fund this new initiative?

## What is the role of the registered nurse?

The Royal College of Nursing defines the role of the registered nurse as follows:[5]

- Nursing is a safety critical profession founded on four pillars: **clinical practice, education, research, and leadership**.
- Registered nurses are decision makers. They use clinical judgement and problem-solving skills to manage patient care.
- Registered nurses coordinate the complexity of health and social care systems to ensure people and their families are enabled to improve, maintain, or recover health by adapting, coping, and returning to live lives of the best quality, or to experience a dignified death.
- Registered nurses have high levels of autonomy within nursing and multi professional teams, and they delegate to others – including nursing associates – in line with the NMC code.
- Registered nurses supervise the work of the nursing team, and in this role will remain professionally accountable for that supervision.



- Registered nurses use evidence-based knowledge, professional and clinical judgement to assess, plan, implement and evaluate high quality person-centred nursing care.
- The work of registered nurses consists of many specialised and complex interventions. Their vigilance is critical to the safety of people, the prevention of avoidable harm and the management of risks regardless of the location or situation.
- The responsibility of registered nurses includes leading the integration of emotional, physical, organisational, and cognitive nursing work to meet the needs of people, organisations, systems, and populations.

[5] Definition and Principles of Nursing | Royal College of Nursing (rcn.org.uk)

## The need for registered nurses

Low staffing of registered nurses on wards can increase patient mortality by up to 26%.[6] On the other hand, with every 10% rise in the number of degree educated nurses, patients are 7% less likely to die.[7]

Safe and effective nurse staffing levels reduce readmissions, health care associated infection rates, medication errors, falls, and pressure ulcers. Safe nurse staffing levels ensure patients receive safe and effective hydration, nutrition and communication.[8]

It allows nursing staff time to care for people in a way that is compassionate and sensitive to their needs.

### The Mid Staffs Hospital Scandal

The Mid Staffs Hospital Scandal underlined just how crucial nurses are to patient safety and why a short staffing of nursing costs lives.


Between January 2005 and 2008, at least 400 more people lost their lives at Stafford hospital than would be normal for a hospital of its size, in what is widely considered one of the biggest scandals in the NHS's 75-year history.

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[6] Rafferty AM, Clarke SP, Coles J, Ball J, James P, McKee M, Aiken LH. Outcomes of variation in hospital nurse staffing in English hospitals: cross-sectional analysis of survey data and discharge records. Int J Nurs Stud. 2007 Feb;44(2):175-82. doi: 10.1016/j.ijnurstu.2006.08.003.

[7] Aiken LH, Sloane DM, Bruyneel L, van den Heede K, Griffiths P, Busse R, Diomidous M, Kinnunen J, Kózka M, Lesaffre E, McHugh MD, Moreno-Casbas MT. Rafferty AM, Schwendimann R, Scott PA, Tishelman C, van Achterberg T, Sermeus W. Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study. The Lancet. 2014 May;383(9931):1824-1830. doi: 10.1016/S01406736(13)62631-8.

[8] Rafferty, A.M et al. (2007). Outcomes of variation in hospital nurse staffing in English hospitals: cross sectional analysis survey data and discharge records. International Journal of Nursing Studies. 44(2), 175-82. https://doi.org/10.1016/j.ijnurstu.2006.08.003

An inquiry headed by Robert Francis KC found that one of the principal causes of the scandal was low staff-to-patient ratios.[9] The Trust had put cash before care, reducing its already low numbers of nurses and handed those left an impossible task. It is imperative that lessons are learnt and that this is never repeated.

## What are nursing associates?

- Nursing associates in England have been part of the NMC register since 2018. The role was introduced in response to the Shape of Caring review (2015)[10] to help build the capacity of the nursing workforce and the delivery of high-quality care (HEE) Health Education England. The purpose was to provide a bridging role between unregistered healthcare assistants and registered nurses (RNs), filling a perceived skills gap and offering an alternative route into nursing.

- When the role of the nursing associate was first introduced into England, the Royal College of Nursing produced job description and preceptorship guidance, in collaboration with Health Education England and others.[11]

- NAs are part of the nursing workforce, who have gained a Foundation Degree, and are accountable for their practice. They are subject to the NMC Code and once practising can undertake further training and education to achieve additional knowledge and skills, enhancing their competence. They must also undertake revalidation, in line with NMC requirements.

- The scope of practice of the NA is to provide, monitor and contribute to integrated care.

## What are the differences between nurses and nursing associates?

The differences between the role of the registered nurse and that of the nursing associate can be summarised as follows: while nursing associates are accountable for the care they provide, it is only the responsibility of the registered nurse to assess care needs, plan, lead and manage care, and evaluate the care provided.

For further information, please see this useful guide that the NMC has produced.[12]

[9] Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry - GOV.UK (www.gov.uk)
[10] Shape of caring review | Health Education England (hee.nhs.uk)
[11] Become a nursing associate | Royal College of Nursing (rcn.org.uk)
[12] Blog: Role differences between nursing associates and nurses - The Nursing and Midwifery Council (nmc.org.uk)

## Potential positive impact of the introduction

If additional funding is available to adequately fund the introduction of nursing associates, and provided that nursing associates are genuinely additional to the existing workforce, this decision could have some positive impacts.

An evaluation of the nursing associates pilot programmes in England, found that 70% of trainee NAs expressed a desire to become registered nurses[13], suggesting that many nursing associates feel valued in their roles. However, it is worth bearing in mind that this progression is not always supported by employers who are often keen to embed the nursing associate role in organisations.[14]

## Concerns over the introduction of nursing associates and potential risks for patient safety

The Royal College of Nursing welcomes the assurance given by the Minister that nursing associates will not substitute registered nurses. Provided that it is the case that this assurance will be reflected in the implementation of the new policy, it is unlikely that the introduction of nursing associates in Wales will put patient safety at risk; however, if that is not the case, then RCN Wales will have serious concerns about the potential risks for patient safety.

An evaluation of the Nursing Associates role in England, published by Kings College London, showed that trusts were developing the role and associated competencies to meet the needs of the services provided, adding to the degrees of variation across employers and settings[15]. This has led to the blurring of boundaries and concerns that nursing associates are being recruited into registered nurse vacancies.

In her letter to RCN Wales Director Helen Whyley, the Health and Social Services Minister acknowledged our concerns that this new role could be used inappropriately as substitution for registered nurses in patient care and stated that she does not support this. RCN Wales very much welcomes this.

Nursing associates cannot replace a registered nurse. Any attempt to replace registered nurses with nursing associates will lead to a sharp increase in patient mortality and will seriously affect patient outcomes.

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[13] https://allcatsrgrey.org.uk/wp/download/nursing/TNA-Year-2-Evaluation-Report_0.pdf

[14] Kessler I, Steils N, Samsi K, Moriarty J, Harris J, Bramley S and Manthorpe J (2020a) Evaluating the Introduction of the Nursing Associate Role in Health and Social Care: Interim Report. NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London. Nursing Associates Interim Report 2020.docx (kcl.ac.uk)

[15] Evaluating the Nursing Associate Role: Initial Findings | Health & Social Care Workforce: (kcl.ac.uk)

Further information regarding the Royal College of Nursing's view on the role of the nursing associate can be found here.[16]

*Role substitution*

The evidence is very clear that it is the professional knowledge, skills and judgement of the registered nurse in a supervisory position that makes the critical difference to patient safety and outcomes. Yet role substitution – the use of support staff for roles and tasks that require a registered nurse – is a very real risk.

Role substitution happens when employers in both the NHS and independent sector, struggling to fill gaps in their registered nursing workforce, resort to simply changing the level of the vacant registered nurse post to that of an assistant practitioner (AP), nursing associate, or health care support worker (HCSW). It has also been linked to a heightened risk of patient death, according to a study published by BMJ Quality and Safety (2016).

It would also be problematic to replace healthcare support workers with nursing associates: healthcare support workers are an essential part of a health or social care team, providing high quality and compassionate care to individuals, carrying out well defined routine clinical duties and essential fundamentals of care.

Support staff such as HCSWs and APs are a vital part of the nursing workforce. Nursing support workers may have different levels of experience, qualifications, and specialisms, and a variety of job titles to reflect this such as Assistant Practitioner. Their contribution is both invaluable and different from that of a registered nurse. It is important that support staff have the clinical supervision and direction of a registered nurse. They should never be pressured to work beyond their competencies or scope of practice, nor should they be used to substitute registered nurses or fill registered nurse vacancies. The Nurse Staffing Levels (Wales) Act 2016 is unambiguous in saying that while a registered nurse may delegate duties to other staff, it is the nurse's presence that matters for patient safety:[17]

*"The number of nurses means the number of registered nurses (this being those with a live registration on Sub Parts 1 or 2 of the Nursing and Midwifery Council register). In calculating the nurse staffing level, account can also be taken of nursing duties that are undertaken under the supervision of, or delegated to another person by, a registered nurse"*

Developing new roles such as assistant practitioners and nursing associates should not be taken lightly. Their purpose should be clearly defined before introduction. The risk of

[16] Registered nurse substitution | Professional Nursing | Royal College of Nursing (rcn.org.uk)

[17] Nurse Staffing Levels (Wales) Act 2016 (legislation.gov.uk)

patients receiving substandard care – resulting in direct or indirect harm – is significant. There should be no possibility of inappropriate role substitution with the introduction of new roles in either health or social care.

RCN Wales welcomes the Minister's acknowledgement in her letter of the protection the Nurse Staffing Levels (Wales) Act 2016 provides to patient care. Statutory guidance and operational guidance could be refreshed to minimise or mitigate against the risk of role substitution.

**The need for scrutiny**

*" . . . the biggest and most impactful review of nursing in Wales since the since the introduction of the graduate nurse in 2004".*

- The Minister has taken this decision before sharing publicly the findings and recommendations of the work undertaken to gather evidence and stakeholder views.


- The Royal College of Nursing is the professional body representing over **30,0000** registered nurses and healthcare support workers in Wales. It would therefore have been helpful to the Minister to receive our views and advice on this review

which, as she describes in her letter, is "**the biggest and most impactful review of nursing in Wales since the since the introduction of the graduate nurse in 2004**".

RCN Wales welcomes the Minister's statement that she will open a public consultation on the scope of the role but believes that the public also needs to be consulted on the question of whether the nursing associate role should be introduced into Wales at all.

The Minister has expressed her commitment to the Royal College of Nursing towards continued collaborative working between her officials and RCN Wales as the work to introduce this role unfolds. RCN Wales welcomes this.

## Questions over funding

It would be helpful to know more detail about the planned introduction of nursing associates in Wales. An explanation of how this will be funded, for example, would be welcomed. In the interest of effective scrutiny, it is important that the Minister for Health and Social Services is able to answer the following questions:

- **How much money is needed to introduce nursing associates in Wales?**
- **How much money is being allocated towards this?**
- **From what budget will the funding come?**

The Welsh Government has not yet made clear how much money will be needed to introduce this new role in NHS Wales, how much money it is planning to spend on this plan nor from what budget this funding will come.

If this new role is intended to be an enhancement of the nursing care offered to patients, then the funding provided for this role must be in addition to the funding already provided for the education and retention of registered nurses.

Essential services are already overstretched and underfunded; unless clarity is given regarding on the issue of funding, it is difficult to know how exactly the introduction of the nursing associate role will benefit patients.

Coleg Nyrsio Brenhinol Cymru
Royal College of Nursing Wales

**Royal College of Nursing**
Ty Maeth
King George V Drive East
Cardiff
CF14 4XZ

**Helen Whyley, RN, MA**
Director, RCN Wales

Telephone [redacted]
Email [redacted]

12 February 2024

Russell George MS
Chair of Senedd Health and Social Care Committee

Emailed to: russell.george@senedd.cymru

Dear Russell

I am aware that the Senedd Health and Social Care Committee is currently in the process of writing its inquiry report into Nurse Staffing Levels (Wales) Act 2016: post-legislative scrutiny. The Royal College of Nursing was very grateful to have had the opportunity to provide evidence to the Committee on 17 October 2023 as part of the inquiry.

I write to you today to request that the Health and Social Care Committee considers the implications of the Welsh Government's recent publication of its intent to introduce the registered nursing associate role in Wales, as part of its forthcoming report into Nurse Staffing Levels (Wales) Act 2016: post-legislative scrutiny.

I was informed by the Minister for Health and Social Services, who wrote to me on 18 December 2023, that she does "*not support RN substitution and consider the Nurse Staffing Levels (Wales) Act facilitates a degree of mitigation for Wales*." RCN Wales shares the Minister's concerns about the potential risks for role substitution and welcomes her commitment to mitigate against these risks as the registered nursing associate role is introduced.

In the interests of patient safety, RCN Wales believes that the Minister for Health and Social Services should consider extending the duties in section 25B of Nurse Staffing Levels (Wales) Act 2016 to include all areas in which registered nursing associates will be employed.

Continued.....

I therefore ask the Committee to explore recommending, as part of your forthcoming report, that the Health and Social Services Minister considers extending section 25B of the Nurse Staffing Levels (Wales) Act 2016 to include all areas in which registered nursing associates will be employed both in and outside of the NHS.

For ease of reference, I have attached a separate letter and briefing that I sent to the Health and Social Care Committee on 31st January, which include further information on the nursing associate role.

I look forward to reading the Committee's forthcoming report.

Yours sincerely

**HELEN WHYLEY, RN, MA**
**DIRECTOR, RCN WALES**

**Encs.**

Eluned Morgan AS/MS
**Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol**

**Minister for Health and Social Services**

Llywodraeth Cymru
Welsh Government

Russell George MS
Chair of Health and Social Care Committee
Senedd Cymru
Cardiff Bay
Cardiff
CF10 4PH

SeneddHealth@senedd.wales

12 February 2024

Dear Russell,

I am writing to you to draw your attention, and that of the committee's, to the launch of the consultation on amendments to the 'Putting Things Right' process and National Health Service (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011.

The consultation is launched 12 February 2024 and closes on the 6th May 2024.

https://www.gov.wales/proposed-changes-putting-things-right-process

Your sincerely,

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

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**Pwyllgor yr Economi, Masnach a Materion Gwledig**
—
**Economy, Trade, and Rural Affairs Committee**

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The Rt Hon. Elin Jones MS
Llywydd and Chair of the Business Committee

20 February 2024

Dear Llywydd,

In line with Standing Order 11.19.2, I am writing to request permission from Business Committee to hold an extraordinary meeting of the Economy, Trade and Rural Affairs Committee on Thursday 14th of March. I have included an indicative agenda below.

The Committee intends to use this meeting time to take evidence from the Secretary of State for Wales as part of our work on the Future of Welsh Steel. Due to the urgent nature of this work, Members would like to hear from the Secretary of State as soon as possible. After exploration of possible dates between the clerking team and the Minister's office, this is the closest appropriate time we could take this evidence.

The Culture, Communications, Welsh Language, Sport, and International Relations Committee and the Health and Social Care Committee have meetings scheduled on the 14th of March. Hefin David MS is a member of both our Committee and the Culture, Communications, Welsh Language, Sport , and International Relations Committee. They are anticipating a finishing time of 13:30 for their meeting. I have made arrangements with Hefin and he is content with the short turn around between Committees on the day. We also share a Member with the Children, Young People and Education Committee who have a reserve slot on the 14th of March. They are considering using that reserve slot, however if they do they anticipate their meeting will finish at 11:00 so this should not pose any issues.

Indicative agenda:

13:35-13:45 – Private pre-meet
13:45-14:45 – Future of Welsh Steel: Secretary of State for Wales
14:45-14:55 – Private consideration of evidence

I have copied this letter to Delyth Jewell MS in her capacity as Chair of the Culture, Communications, Welsh Language, Sport, and International Relations Committee; Jayne Bryant MS in her capacity as Chair of the Children, Young People and Education Committee and Russell George MS in his capacity as Chair of the Health and Social Care Committee for their information.

Kind regards,

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

We welcome correspondence in Welsh or English

GIG CYMRU NHS WALES
Iechyd a Gofal Digidol Cymru
Digital Health and Care Wales

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14 February 2024

Russell George MS
Chair
Health & Social Care Committee

Mark Isherwood MS
Chair
Public Accounts and Public Assurance Committee

Dear Russell and Mark,

## DHCW Follow-up Response to the Welsh Parliament Health and Social Care Committee and Public Accounts and Public Administration Committee Scrutiny of Digital Health and Care Wales Report

DHCW provided their response to the Public Accounts and Public Administration Committee and the Health and Social Care Committee joint report on 16th August 2023. The report contained 16 recommendations, all of which were responded to.

Of the 16 recommendations, 3 required a further update by the end of 2023 which we were pleased to provide on 19 December 2023.

A further 3 recommendations required an update by the end of February 2024. These recommendations and our updated responses are detailed below:

**Recommendation 3:** The Welsh Government and Digital Health and Care Wales should provide the Health and Social Care Committee and the Public Accounts and Public Administration Committee with six-monthly updates on progress on the delivery of the Welsh Community Care Information System. The updates should include information about expenditure to date, planned expenditure, uptake of WCCIS among health boards and local authorities, engagement or consultation undertaken with relevant partners. The first update should be provided in the responses to this report.

**DHCW Response to Recommendation 3:** Please refer to our Programme Delivery Committee Papers published on the DHCW Internet Site. The papers contain an update on the delivery of the Welsh Community Care Information System.

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**Recommendation 10:** Digital Health and Care Wales should provide further evidence about the human resource systems and capacity available to facilitate the recruitment and retention of specialist skills. This should include information identifying where the key gaps and vacancies are, how actions to address the gaps are being prioritised, and what steps are being taken to mitigate the risks to delivery arising from the vacancies. Following the provision of this information in its response to this report, DHCW should provide the Health and Social Care Committee and the Public Accounts and Public Administration Committee with six-monthly progress updates.

**DHCW Response to Recommendation 10:** A Strategic Resourcing Group, established in 2022, chaired by the Director of People and Organisational Development continues to meet to ensure skills gaps are recognised and addressed to mitigate the risks arising from vacancies. Please refer to the DHCW January 2024 Board Papers and February 2024 Audit and Assurance Committee Papers and for updates on Strategic Workforce Planning.

**Recommendation 15:** Digital Health and Care Wales should engage with its partner organisations to evaluate its existing approaches to collaboration and identify areas for improvement and opportunities to strengthen relationships. In its response to this report, Digital Health and Care Wales should outline how it will undertake this evaluation. It should then provide the Health and Social Care Committee and the Public Accounts and Public Administration Committee with six-monthly updates on how it is collaborating with its partners and what such collaboration has achieved.

**DHCW Response to Recommendation 15:** We previously referred you to our September 2023 Board Papers published on the DHCW Internet Site which contained a detailed update outlining progress against our Stakeholder Engagement Plan. We have an established programme of engagement including regular strategic sessions with our key partners to support collaborative delivery of agreed joint plans. This includes NHS Wales partners, commercial partners and national bodies and organisations. As part of this programme of work and also through our wider listening and learning approach, we have strong feedback mechanisms, including partnership workshops, focus sessions, and discovery projects. We are enhancing this with an independently delivered stakeholder survey. DHCW has recently been out to tender for this work but we were unable to appoint a supplier. We are working through delivery options for an independent survey, whilst continuing our internal work on reflective workshops and feedback sessions. We will continue to provide six monthly updates to our Board, the next is scheduled to go to our SHA Board public meeting on the 28 March 2024.

GIG CYMRU NHS WALES
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Yours sincerely,

Helen Thomas
Chief Executive

Simon Jones
Chair

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

**Julie Morgan AS/MS**
**Y Dirprwy Weinidog Gwasanaethau Cymdeithasol**
**Deputy Minister for Social Services**

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



Llywodraeth Cymru
Welsh Government

Our Ref: MA/EM/3244/23

Russell George MS
Chair
Health and Social Care Committee

SeneddHealth@senedd.wales

27 February 2024

Dear Russell

Following the Health and Social Care committee's draft budget scrutiny session scheduled for 17 January, we are writing to provide you with the further information and papers that were requested during the session.

Firstly, we agreed to provide you with a copy of the letter setting out the NHS Wales Planning Framework 2024-27 issued to health boards in December. Please find this attached to letter.

We also agreed to provide figures for the estimated cost of offering an additional 1% uplift to medical and dental staff. This was in reference to the position of industrial action being taken by junior doctors. Please note, this is just to provide figures and it is not an offer to increase the pay award for medical and dental staff in Wales for 2023-24. The Doctors and Dentists Remuneration Body (DDRB) made recommendations for a 6% pay award for doctors and dentists. In addition to a 6% uplift, it also recommended that junior doctors pay points also had a consolidated pay rise of £1250.

The costs for meeting DDRB in full on top of the 5% award already given this year would cost in the region of an additional £21.8m recurring (this includes the additional 1% plus the £1250 consolidated for junior doctors).

The costs for meeting just the 1% increase on medical and dental would be £13.2m recurring. Broken down as follows by doctors and dentists:

- Consultants: £5.5m
- Specialty and associate specialist doctors: £1m
- Junior doctors (1%): £2.9m
- Junior doctors £1250 uplift consolidated: £8.6m
- General medical practitioners: £1.8m
- General dental practitioners: £2m

The 5% pay offer has been made consistently to all NHS staff groups, including Agenda for Change, all hospital medical staff (including junior doctors) and primary care GPs and dentists. The total costs of an additional 1% pay uplift for all NHS staff groups in 2023-24 would be around £58m.

Next, you asked for the cost of the recent industrial action, broken down by health board, both in terms of staffing and levels of activity. NHS Wales has been working on collating the overall net impact of the recent industrial action by junior doctors. Organisations have been validating information to be clear on those who did participate and those did not. It is taking longer than expected to work through every aspect of where some of those impacts fall and the exact costs. Organisations are working on producing a net cost after taking into account any cost reductions, for example, due to activity being lower from cancelled procedures. This is happening as part of their normal monthly reporting cycle.

The indication we have so far is only from draft returns but suggests that the net financial impact will be between £3m to £4m. This estimate will be refined further once organisations have completed their analysis.

You also asked if we could make an assessment of how much of the agency spend over the last few years is represented as profits for private companies. Unfortunately, it is not possible to provide an assessment of levels of profit in staffing agencies supplying the NHS. This information is not available publicly and cannot be reasonably deduced from published financial information, therefore we cannot speculate on the levels of profit in these private companies. It is worth noting that many of these companies also deal with other customers outside of the NHS.

The Deputy Minister of Mental Health and Wellbeing agreed to provide further details of how the resources for the children and family pilots were being targeted. The Children and Family Pilots (branded PIPYN) are based on the Public Health Wales' Every Child Wales 10 Steps to a Healthy Weight. The intervention consists of one-to-one family support within a wider systems-based approach that looks to enable families and their young children to be more active and eat more healthily. The intervention is aimed at families with young children (age three to seven) who are obese or are at risk of becoming obese. As part of the one-to-one support, an initial conversation takes place with the family.

The Family Support Worker helps the family to set personalised goals based on the following themes:

- Activity Levels (active play and recreation as a family)
- Dietary Choices (what food is bought)
- Family food environment (regular meal times, snacks)
- Parenting (food as reward, screen time, sleep routines, cooking from scratch)
- Parents model healthy behaviours (parent's food and activity choices)

The family support workers help the family to meet these goals through weekly sessions over eight weeks. If the family need help buying healthy food, this could include helping the family to put together a weekly meal plan on a budget. If families rarely cook meals from scratch, the support could include referral to their local 'Come and Cook' provider. Come and Cook with your child is a Nutrition Skills for Life programme in which nutrition and practical cookery skills are held for parents and their children at a local school. Come and Cook is a programme that is being supported by the three children and family pilots in Cardiff, Anglesey and Merthyr as part of their wider systems-based approach. Betsi Cadwaladr University Health Board are also supporting Come and Cook and have expanded the programme into secondary schools as part of their Healthy Weight Healthy Wales whole system approach. In Merthyr alone, almost 200 families

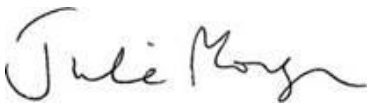
have completed or are signed up to the programme and 38 families have completed the cooking sessions.

Finally, on 7 February the Deputy Minister of Mental Health and Wellbeing wrote to the committee on the subject of substance misuse services, and we trust this satisfies your request for further information.

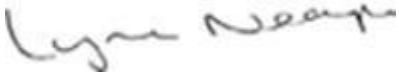
We hope this information is useful.

Yours sincerely

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



**Julie Morgan AS/MS**
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol
Deputy Minister for Social Services



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

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

Llywodraeth Cymru
Welsh Government

Our ref: MA/EM/3060/23

NHS Chairs

18 December 2023

Dear Colleagues,

**NHS Wales Planning Framework 2024-2027**

I am writing to set out the statutory planning Directions for NHS organisations that clarify the requirements for the coming year. This will set the ambition and direction for your plans over the three-year period.

Integrated planning, rather than through the market, is the way that NHS services are delivered in Wales. The NHS (Wales) Act 2006, as amended by the NHS Finance (Wales) Act 2014, sets out requirements for NHS planning in Wales. Under the legislative framework, local health boards and NHS trusts, have a statutory duty to prepare a plan, which is submitted to and approved by the Welsh Ministers, and which sets out how their organisation will secure compliance with their financial break-even duties while improving the health of the people for whom they are responsible and the provision of healthcare to such people. To satisfy these duties, the boards of those organisations must submit a three year Integrated Medium Term Plan (IMTP) for my consideration.

This Framework is set in the most challenging circumstances that the NHS has had to deal with since its inception. This is primarily as a result of the legacy from covid and Brexit, the challenging financial outlook and the wider system pressures on workforce and the cost-of-living position. Given the unprecedented challenges, operational, workforce, demand and financial pressures, it is crucial that our resources are optimised to deliver the best care and treatment for the people of Wales. Organisational plans will set out the improvements to be made to services and their future sustainability within the resources available to reduce inequalities and to improve the health outcomes of the populations you serve.

The Well-being of Future Generations (Wales) Act 2015 set in law the need to consider the long-term strategic approach to deliver a better future. This was underpinned by ‘A Healthier Wales’, and which remains the vision and long-term plan for health and social care in Wales. I have asked for the actions in A Healthier Wales to be reviewed and refreshed to ensure that they reflect the current and expected challenges over the coming years. This work will be undertaken over the coming months. Following the refresh of the A Healthier Wales actions, your plans will be assessed and aggregated into a national picture to determine how far they go in delivering that vision. Clarity of delivery commitments within your plans is therefore vital.

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Improving population health outcomes continues to drive our strategic planning ambitions. We must understand the impact of the burden of disease modelling and the opportunities this provides to plan our services. The recent Senedd debate on the Chief Scientific Adviser's report – NHS in 10+ years – recognises the pressures the system will face as almost a fifth of the Welsh population will be aged 70 or above, those with diabetes could rise by almost 22% and the number of people suffering four or more chronic conditions could double. This shows that wherever possible a focus on prevention should be taken to stabilise the NHS to reduce acute demand for both the medium and the longer term. This includes initiatives such as weight management and diabetes that will support health outcomes and reduce pressure on health services over time.

To do this, it is essential that we make prudent use of our resources through quality and value-based approaches that ensure that there is a reduction in waste, harm and unwarranted variation. There are already excellent examples in terms of diabetes and cardiac through the Welsh Value in Health programme that must be drawn on to consistently implement high value interventions and reduce those that are of lower value, while delivering best outcomes for patients.

In this financial year you will know the significant work that was undertaken in-year to identify and allocate more funding to the NHS, reduce deficits and the delivery expectation I have set for target control totals by Health Board. Progress is being made by a number of organisations with further work required to deliver the control totals set. Next year's financial outlook remains very challenging, and my expectation is that the actions delivered this year are maintained on a recurrent basis, before identifying the further improvements that must be made in efficiency and savings for 2024-25.

The allocation and budgetary framework for the NHS will be issued once the Welsh Government draft budget is issued on the 19 December, and it is crucial that NHS organisations make further progress towards financial sustainability.

Plans must take advantage of transformation, innovation and digital opportunities in designing services and treatment pathways. Digital developments are essential to transforming efficiency, access and care, for example, through an ambition to have a paperless NHS. Digital transformation will also ensure the quality and safety of patients. All these elements will support preventative work and make a difference to stabilise the system in the short term as well as help mitigate some of the unrelenting pressures on services.

Primary and community care sees around 90% of the patients in contact with the NHS in Wales. A Healthier Wales made clear that shifting resources and making sure that more patients can be seen, diagnosed and treated in the community was key to long term improvements in health. Helping people to stay well at home will rely heavily on genuine collaboration and partnership across the health, social care and third sectors. If we are to see transformational change in our health and care services, to make it fit for the next 75 years, we need to make that change a reality. I want to see organisations embracing the plans coming forward from the Accelerated Cluster Developments and the Regional Partnership Boards; showing primary and community care as a bedrock of the IMTPs and progressing the cross programme work to develop a consistent Enhanced Community Care model for Wales.

It is clear that the ongoing pressures are having a disproportionate impact on children and young people as well as exacerbating health inequalities. Attention must be given to the quality and levels of services to ensure that women and children, and other sections of the communities in Wales, are not disadvantaged in accessing care and treatment. Attention must be given to reducing health inequalities experienced by sectors of our communities.

Reductions in some health inequalities can be achieved by identifying gaps in health service provision, considering areas of best practice and developing actions to address these gaps. Equitable access to all services remains at the centre of the values of the NHS in Wales and even more so when the impact can have a disproportionate effect during the 'cost of living' crisis. I encourage you to take account of these areas in your planning.

The national programmes will continue to support the delivery of services that make the most of the finite resources available. They must not drive costs but reinforce best practice through quality, efficiency, and patient experience. The National Programme areas remain:

- Enhanced Care in the Community, with a focus on reducing delayed pathways of care.
- Primary and Community Care, with a focus on improving access and shifting resources into primary and community care.
- Urgent and Emergency Care, with a focus on delivery of the 6 goals programme.
- Planned Care and Cancer, with a focus on reducing the longest waits.
- Mental Health, including CAMHS, with a focus on delivery of the national programme.

The accountability conditions for these programmes were issued in September and will provide continuity between 2023 and 2024 plans.

To provide guidance and support the Value and Sustainability Board, chaired by Judith Paget, has agreed five workstreams to maximise resource utilisation across the system. The thematic areas are:

- Workforce
- Medicines Management
- Continuing Health Care (CHC)/Funded Nursing Care (FNC)
- Procurement and non-pay, and
- Clinical Variation/Service Configuration

The Board has already issued a range of requirements in relation to low value interventions, prescribing and continuing health care that must be implemented to ensure a consistent approach across Wales. I want to see material progress made across all workstreams.

As part of the Value & Sustainability agenda I am clear in my expectation that for 2024-25 there must be a consistent and significant impact in the following areas on both a local and national basis, I will be asking my officials to focus on ensuring these are delivered, and progress on these areas will be a key feature of assessing organisations plans:

- Continued progress in reducing the reliance on high-cost agency staff.
- Ensuring strengthened 'Once for Wales' arrangements to key workforce enablers such as recruitment, and digital.
- Maximising opportunities for regional working.
- Redistributing resources to community and primary care where appropriate and maximising the opportunities offered by key policies such as Further Faster.
- Reducing unwarranted variation and low value interventions.
- Increasing administrative efficiency, to enable a reduction in administrative and management costs as a proportion of the spend base.

NHS Wales commands a major share of the Welsh Government's budget. It is therefore incumbent upon NHS organisations to ensure that the role as Anchor Institutions is fully exploited. I want to see NHS organisations demonstrate their contributions to the foundation economy, the climate change agenda, as well as supporting the wider Welsh Government goals; demonstrating the partnership and collaboration opportunities across sectors that comes with this responsibility.

As we strive to progress immediate operational delivery in this challenging environment, we must not lose sight of the future health improvements we aspire to. Applying the sustainable development principle (5 ways of working) consistently will allow us to reap the benefits of the Wellbeing of Future Generations (Wales) Act 2015. Complementing this groundbreaking legislation are two other recent key Acts - the Health and Social Care (Quality and Engagement) (Wales) Act 2020 and the Social Partnership and Public Procurement (Wales) Act 2023, from which further provisions will come into force in April 2024. These provide a context for how NHS organisations should work collaboratively with an unrelenting consideration of quality in all that is done, to deliver the best NHS care consistently across Wales. April 2024 will also see the establishment of the new NHS Wales Joint Commissioning Committee, which will streamline the commissioning landscape.

Judith Paget, NHS Chief Executive, will write to you imminently setting out the process and governance that will underpin your submissions. NHS plans will continue to form a strong foundation for NHS Chief Executive and Chairs' objectives and will be central to our discussions throughout the year.

Finally, my personal thanks go out to all NHS staff for the commitment and care they demonstrate every day that make a difference to patients in Wales. I know you will agree, that we owe it to them to ensure our collective ambitions for improvement in outcomes will be realised.

Yours sincerely,

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

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

Llywodraeth Cymru
Welsh Government

Eich cyf/Your ref
Ein cyf/Our ref
Russell George MS
Chair
Health and Social Services Committee

Cc:
Equality and Social Justice Committee
Children, Young People and Education Committee
Legislation, Justice and Constitution Committee

07 February 2024

Dear Russell,

During my appearance at the Health and Social Services Committee on the 17th January, I agreed to supply details of the Welsh Government's substance misuse funding.

This has been the most challenging budget since devolution but I have prioritised our substance misuse investment to vital frontline services to ensure some of the most vulnerable people in our society continue to have access to services and support. However, this has required some difficult decisions.

In spite of the challenging budget, I have continued to protect our substance misuse funding and this has now, overall, risen to just over £67m. Substance Misuse Action Funding (SMAF) is provided directly to our Area Planning Boards (APBs) and this will rise by £2m in 2024/25 to £41m. This £2m increase in our funding will be allocated to the ring-fenced allocations for children and young people and complex needs funding both increasing by £1m, to £6.25m and £4.5m respectively. In addition, within the £41m we will continue to support the highly successful use of injectable buprenorphine (Buvidal) with £3m, over half of which supports criminal justice prescribers in the community. Health Boards receive funding for their substance misuse treatment services through their allocation letters and this will increase by £812k to just over £22.9m in 2024-25. Details of these funding decisions are at Annex A.

The committee asked for details of any support we provide for Brynawel. We do not fund Brynawel directly from Welsh Government with any revenue funding as placements are

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funded either by local authorities or through the ring fenced £2m for residential treatment provided to APBs. Placements are made, led by service user choice, through our Rehab Cymru framework. However, I'm pleased to say that in February 2023 we awarded Brynawel £795,000 of capital funding for the expansion of their service through the purchase and refurbishment of a neighbouring property.

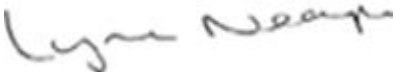
In addition to our funding for substance misuse services, we also continue to support our Out of Work Peer Mentoring Service. The service helps people recovering from substance misuse and/or mental ill-health through peer support and will be funded with £5.4million in 2024-25. The service aims to support up to 10,000 people including 3,000 young people across Wales between its start in October 2022 and March 2025. This service is a successor to the previous European funded service between 2016-2022.

I referred to the Wales Police Schools Programme (WPSP) at Committee. The programme is currently funded through the substance misuse budget but faced with potential cuts to frontline services I have decided to prioritise our substance misuse investment to ensure access to vital services and support. Therefore, I have had to withdraw the Welsh Government's funding contribution of £1.98m per financial year to the programme from the 31st March this year. The landscape around wellbeing for learners on a range of important issues has changed significantly since the introduction of the programme. Many areas are now subject matter that would be considered in mandatory health and well-being learning in Welsh schools. Relationships and Sexuality Education (RSE) covers a number of areas, including substance misuse, online safety and domestic violence. There are further plans to develop more resources for schools to inform learning about a range of health and wellbeing issues and my officials are working with colleagues in education to maximise learning from the programme

My officials will continue to work with the Police to work through the implications of the withdrawal of the Welsh Government's match funding for the programme. The Welsh Government will continue our close relationship with the four Police and Crime Commissioners and forces in Wales and they are valued partners.

I am copying in the chairs of the Equality and Social Justice Committee, Legislation, Justice and Constitution Committee and the Children, Young People and Education Committee.

Yours sincerely



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

Annex A.

| | 2023-24 | 2024-25 | Change |
|---|---|---|---|
| Substance Misuse Action Fund | £39.063m | £41.063m | +£2m |
| Wales Police Schools Programme | £1.980m | £0 | -£1.980m |
| Drug & Alcohol* | £1.542m | £1.022m | -£520k |
| Capital | £2.5m | £2.5m | £0 |
| Health Board ring fence | £22.102m | £22.912m | +£812k |
| **Overall total** | **£67.187m** | **£67.497m** | **+£312k** |

*The Drug and Alcohol Budget supports key central services and activity. These include Public Health Wales, WEDINOS, Naloxone and evaluations of both MUP and Buvidal.

# Agenda Item 8

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# Agenda Item 9

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

Agenda Item 11

Llywodraeth Cymru
Welsh Government

Russell George MS
Chair,
Health and Social Care Committee

SeneddHealth@senedd.wales

19 February 2024

Dear Russell

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

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

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

Yours sincerely

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

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

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

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

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

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

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

In response to the specific recommendations made:

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

Response: Accept

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

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

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

Response: Accept in part

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

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

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

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

Response: Accept in principle

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

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

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

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

Response: Reject

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

Financial Implications: none, the recommendation is rejected.

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

Response: Accept

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

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

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

Response: Accept

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

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

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

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

Response: Accept

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

Financial Implications: none, within existing programme resources.

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

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

Response: Accept in part

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

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

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

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

Response: Accept

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

Financial Implications: none, within existing resources.

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

Response: Accept

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

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

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

Response: Accept

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

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

Financial Implications: none, within existing resources.

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

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

Response: Accept in part

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

Financial Implications: within existing resources.

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

Response: Accept

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

Financial Implications: none, is included within existing resources.

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

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

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

Response: Accept in part

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

Financial Implications: none.

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

Response: Reject

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

Financial Implications: none, the recommendation is rejected.

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

Response: Accept

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

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

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

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

Response: Accept in principle

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

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

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

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

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

Response: Accept

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

Financial Implications: none.

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

Response: Accept

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

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

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

Response: Accept

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

Financial Implications: none, within planned resources.

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

Response: Accept

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

Financial Implications: none, within planned resources.

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

Response: Accept

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

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

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

Response: Accept

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

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

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

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

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

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

Financial Implications: none, within planned resources.

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

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

Response: Accept

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

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

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

Financial Implications: none, with planned resources

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

Response: Accept

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

Financial Implications: none, included within existing resources.

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

Response: Accept

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

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

Financial Implications: none, included within programme resources.

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# Agenda Item 12

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