

Agenda – Health and Social Care Committee

Meeting Venue:

Hybrid – Committee Room 4 Ty Hywel
and video conference via Zoom

Meeting date: 19 June 2024

Meeting time: 09.30

For further information contact:

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Committee Clerk

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Private pre-meeting (09.00–09.30)

1 Introductions, apologies, substitutions, and declarations of interest

(09.30)

2 Supporting people with chronic conditions: evidence session with the Cabinet Secretary for Health and Social Care

(09.30–10.45)

(Pages 1 – 49)

Eluned Morgan MS, Cabinet Secretary for Health and Social Care

Heather Payne, Senior Medical Officer Maternal & Child Health

Welsh Government

Stuart Hackwell, Senior Medical Officer for Primary Care and Mental Health

Welsh Government

Research brief

Paper 1 – Welsh Government

3 Paper(s) to note

(10.45)

3.1 Letter from the Llywydd to the Chairs of the Health and Social Care Committee and the Legislation, Justice and Constitution Committee regarding legislative competence and human rights considerations in the Health and Social Care (Wales) Bill

(Pages 50 – 54)



- 4 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the remainder of today's meeting**

(10.45)

Break (10.45–11.00)

- 5 Supporting people with chronic conditions: engagement findings**

(11.00–11.15)

(Pages 55 – 83)

Paper 2 – Supporting people with chronic conditions: engagement findings

- 6 Supporting people with chronic conditions: consideration of evidence and emerging themes**

(11.15–12.00)

Document is Restricted

Eluned Morgan AS/MS
Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol
Cabinet Secretary for Health and Social Care



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: MA/EM/5341/24

Russell George MS
Chair of Health and Social Care Committee

SeneddHealth@senedd.wales

4 June 2024

Dear Russell,

Ahead of the Health and Social Care Committee's meeting on 19 June 2024, please find attached the Welsh Government's evidence paper covering the topic 'supporting people with chronic conditions'.

Yours sincerely,

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

Eluned Morgan AS/MS
Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol
Cabinet Secretary for Health and Social Care

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

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

Welsh Government’s Evidence Paper on Supporting People with Chronic Conditions

Health and Social Care Committee – 19 June 2024

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What is required to enable services to better meet the needs of people with multiple conditions (often referred to as “multimorbidity”)

One of the successes of our healthcare system over the past 70 years, has been that people in Wales are living longer. However, more of us are living with one or more long term conditions. Multimorbidity is the term used to describe individuals who have two or more coexisting conditions, such as chronic obstructive pulmonary disease (COPD), cardiovascular disease (CVD) and diabetes. This is a growing global challenge with substantial effects on individuals, carers and society.

Multimorbidity occurs around a decade earlier in socioeconomically deprived communities and is associated with premature death, poorer function and quality of life, and increased health-care utilization. The mechanisms underlying the development of multimorbidity are complex, interrelated, and multilevel, but are related to ageing, underlying biological mechanisms, and broader determinants of health, such as socioeconomic deprivation. Optimising how we support people with multimorbidity is likely to be beneficial and must remain an area of focus, as well as maintaining a focus on prevention and the psychosocial and behavioural factors that increase the risk of developing multiple long-term conditions, particularly population level interventions.

In 2018, in response to the parliamentary review which set out the case for change in order to respond to the changing needs of the population, the Welsh Government published its vision for care and support in [A Healthier Wales](#) (AHW).

AHW highlights the need for better management of long-term conditions within the healthcare system and the need to give patients the confidence and ability to manage their conditions (self-management). There is a need to shift services closer to home and to ensure the workforce is resourced to manage not only an increasing population but also increasing the individual patient demands that result from suffering from more than one long term condition.

Multimorbidity is further highlighted in the [National Clinical Framework - A Learning Health and Care System](#) published in March 2021. The National Clinical Framework highlights that the existing clinical model in Wales is speciality focused and there is a need to shift to a patient focused approach. Although the new National Strategic Clinical Networks (Networks) within the NHS Wales Executive (the Executive) each focus on specific conditions, there is also a key role for Networks to consider multimorbidity, both individually and collectively.

Across the UK, improvements in mortality rates have slowed down in the last 10-15 years, manifesting in lack of improvement in life expectancy. This slow-down in mortality improvement can be attributed to a number of factors including reduced improvement in mortality from CVD, increased multimorbidity, and vulnerability to respiratory disease and other winter risks in an ageing population.

For diabetes alone, Public Health Wales (PHW) estimates that on current trends, one in eleven adults in Wales could be living with the condition by 2035 – 90 per cent of which would be Type 2 diabetes, around half of which could be preventable with lifestyle changes. Regarding CVD, stroke is the fourth biggest killer in Wales and a

leading cause of disability. There are currently almost 70,000 stroke survivors living in Wales. With an estimated 7,400 people experiencing a stroke in Wales each year, and more people surviving stroke, the number of stroke survivors is expected to increase by 50 per cent during the next 20 years. An estimated 70 to 90 per cent of strokes are due to modifiable risk factors, including high blood pressure and atrial fibrillation, smoking, drinking too much alcohol, and are preventable through effective primary and secondary care intervention and public health action. Diabetes is of course a risk factor for stroke and addressing the many compounding factors to reduce the risk of developing diabetes will by default reduce the incidence of stroke.

In recent times we are seeing a move from a focus on single-disease issues to recognising that people suffer from more than one chronic condition and the rise of multimorbidity. Some examples of this are provided [below](#). This is a positive sign of the urgent shift needed towards supporting people with multimorbidity.

Workforce

To support this further, the health and care system must also overcome the challenges in the way the workforce is trained and shaped. For a generation, most clinical practice guidelines and health-care training and delivery has focussed on single diseases, leading to care that is fragmented, sometimes inadequate, and potentially harmful. Importantly, for people themselves the single condition focus places a treatment burden on those with multiple conditions that can sometimes be difficult to manage. For example, attending multiple appointments and undergoing investigations, having to repeat their story multiple times, managing multiple interacting medications and their side effects, managing fragmented care and navigating a complex system, trying to manage changes in treatment regimens and care plans, and also trying to learn about their conditions and make necessary behavioural and lifestyle changes.

We must do all that we can to support our future workforce to have a broader understanding of prevention and [Making Every Contact Count \(MECC\)](#), and in the complexity of managing multiple interacting conditions. Embedding the principles of shared decision making is pivotal to ensuring effective person-centred clinical and care planning decisions which are grounded in the wellbeing and quality-of-life outcomes and goals that matter to individuals.

Our pre-registration nurse, midwifery and health professional education programmes incorporate learning on positive approaches to supporting people with multiple conditions both within curricula and during practice-based learning (up to 50% of healthcare student programmes). Placement learning opportunities across primary and community care, secondary care and wider service sectors include working within services supporting individuals with multiple conditions. Students have opportunities to be involved in the coordination of care across specialities including screening clinics and acute interventions for chronic conditions (diabetes; coronary heart disease; asthma; thyroid disorders; hypertension; hyperlipidaemia; rheumatoid arthritis; chronic kidney disease; chronic pulmonary disease).

A key element of learning in academic and placement settings involves health promotion and disease prevention, particularly the ability to sensitively and

compassionately support individuals' lifestyle changes that can prevent the onset of chronic diseases; conducting routine screenings and vaccinations to address health issues early; and assisting individuals with necessary information and resources to maintain wellness.

There are also a number of post registration education programmes and standards which include and address comorbidity/multimorbidity. Examples include the General Practice Nursing (GPN) Foundation programme which supports nurses new to general practice to gain skills in hypertension, heart disease, diabetes, asthma and COPD management.

Advanced practice education programmes also contain modules that will involve developing an understanding of altered physiological processes in relation to cardiovascular, respiratory and musculoskeletal disease processes, for example COPD, heart failure, and endocrine, neurological and abdominal disease processes, for example Diabetes and Thyroid disease, Parkinson's disease, liver and gut diseases, and knowledge and skills in relation to examining patients with these conditions.

In addition, the Allied Health Professional Programme is also supporting implementation of [Multi-professional Framework for integrated working](#) and [maturity matrix](#), developed by the Strategic Programme for Primary Care. This includes engaging with service users to develop rehabilitation standards, e.g. the [Community rehabilitation standards](#).

Aligned to the Shape of Training review, the Academy of Medical Royal Colleges has revised its curricula to include an emphasis on generalist training to cope with the increasing demand for doctors who can holistically look after patients with comorbidities.

Management of chronic conditions in primary care is an important part of the GP curriculum. GP Specialty trainees observe and run chronic disease clinics and manage patients with chronic disease in daily consultations.

The Strategic Programme for Primary Care (SPPC) is working to ensure that population health needs including supporting people with multiple conditions are met by services in primary and community care. HEIW are collaborating with the SPPC to ensure that education and training of the workforce empowers them to deliver those services through effective multiprofessional teams.

In April 2024, HEIW launched the strategic workforce plan for primary care. The plan contains several actions that will support delivery of high-quality care for people with multiple conditions closer to home. These include building a sustainable GP workforce, education and training for the primary care workforce and appropriate supervision of multi-professional teams.

Specialist assessment is important for some, but supporting people with multimorbidity requires person-centred care, prioritizing 'what matters' most to the individual and the individual's carers, ensuring continuity of care from experienced professionals working in a multidisciplinary way with care that is effectively coordinated, with minimal treatment burden, and aligns with the person's values.

Ageing Well, Older People Frailty and People Living with Frailty

Older people and those living with frailty is one population group that illustrates well the critical importance of the multimorbidity approach. As a well-recognised long-term condition associated with the ageing process, frailty is not an inevitable consequence of ageing but is associated with the presence of multiple interacting conditions. A health and care system attuned to the needs of older people and people living with frailty is essential but challenging to achieve within our current model of health and care, which tends to be weighted towards reactive care and crisis management, and too often results in an avoidable hospitalisation. Achieving optimal quality-of-life outcomes for this population demands a fundamental shift towards a person-centred outcome focussed approach that supports multimorbidity, underpinned by population health management, preventative and anticipatory focussed care, shared decision making and proactive management and care planning. This has been as set out in our complimentary publications; The [Integrated Quality Statement \(IQS\) for Older People and People Living with Frailty](#) and the [Strategy for an Ageing Society](#).

Maximising opportunities for maintaining and improving the health and wellbeing of people as they age and enter their later year must continue be a priority as our population ages, a demographic projection forecasted to be increasingly challenging each year until the mid-part of the century. It must focus on quality-of-life in later years, not just quantity of life; expanding the years spent with good health and wellbeing - shortening and compressing the amount of time a person spends with ill-health and disability. Developing frailty attuned care will not only improve the quality-of-life outcomes for this population, but also benefit others and the system as a whole.

Aligned to AHW, [Building Capacity through Community Care \(BCCC\)](#), acknowledged the existing demand and capacity imbalance across our health and social care system attributed to an increasingly older population. Our strategic goals can only be achieved by building capacity within our communities and within primary and community care. Primary and community care must be the bed rock and strength of our model through a multiple professional approach with expertise in understanding and managing the complexity of multiple interacting conditions that compound each other and can complicate treatment interactions.

Primary and Community Care

The [Primary Care Model for Wales](#) was adopted in 2018 as the agreed approach to organising health and wellbeing services in line with the vision in AHW.

Core to the Primary Care Model for Wales is person-centred care and support with access to the right professional or service at or as close to home as possible. To achieve this, GPs, nurses, pharmacists, dentists, optometrists, allied health professionals (AHPs), social care workers and people working in the third sector collaborate through the clusters to both plan and provide people with a range of ways to access seamless care and support.

Information about individuals is shared appropriately to ensure services are joined-up and provided in a seamless and timely way across the community. Modern technology, local facilities and services are all used to help people lead healthy lives and to support those with an increased risk of urgent care needs, such as people living with several long-term health conditions.

Funding to increase capacity in primary and community care

Welsh Government has provided £8.24m (rising to £11.95m for 2024-25) to increase community health and social care capacity. We have separately invested £5m from 2023-24 to create additional community [Allied Health Professionals](#) (AHPs) and £8.3m to widen access to [Adferiad Funded Services](#). Additionally, in the last year nearly £145 million has been invested through the Welsh Government's [Regional Integration Fund](#), on projects delivered by health and social care partners to provide community services.

We expect this funding to be aligned to ensure a well-integrated, multi professional service response in the community. Health boards and their local authority and wider partners are jointly responsible through the pan cluster planning groups for determining how they will utilise this investment, recognising that plans will need to build on local need and existing services.

The [NHS Wales Planning Framework](#) is issued to the NHS in Wales on an annual basis to inform their planning. The framework sets out the priorities and NHS organisations are required to develop integrated three-year plans each year, setting out how they intend to deliver healthcare services in line with the requirements of the framework.

Within our integrated health system, NHS organisations' plans must draw on their population needs assessments and demonstrate an integrated planning approach predicated on planned and unplanned care settings (discouraging single condition planning), linking population need to quality, service models, capacity requirements, workforce development and capital and financial planning, all set within the context of the organisations' longer term clinical services strategy. Integrated plans must also align with a range of partnership plans, including primary care plans, Area Plans

developed by Regional Partnership Boards, Wellbeing Plans developed by Public Services Boards as part of the Wellbeing of Future Generations Act requirements and Mental Health Delivery Plans developed by Together for Mental Health partnerships.

The development of [NHS Executive](#) signals a new way of working, and the themes set out within their remit from Welsh Government are not specific to disease conditions, settings, or population groups. The NHS Executive includes many national functions and programmes in one entity, and whilst there are differing policy drivers, including Quality Statements, and national programmes, the NHS Executive provides the opportunity to collectively collaborate to align work programmes to ensure a whole system approach.

The NHS Executive has established strategic clinical networks to replace the former condition specific implementation groups and supported the appointment of several new National Clinical Leads. The development of the cardiovascular network is a good example of bringing together a family of networks and partners to improve population outcomes for people with different conditions, that has wider benefits to people and the system as a whole than a single condition approach can provide.

This affords the opportunity for collective collaboration to align work programmes and activity across multiple conditions that require a similar and integrated approach to address some of common lifestyle and other risk factors, and the primary, secondary and tertiary prevention public health activity to address these.

Tackling inequalities and the barriers faced by certain groups, including people living in poverty and people from ethnic minority backgrounds

Tackling health inequalities remains a key priority for the Welsh Government as we continue to recover from the Covid pandemic and the cost-of-living crisis. It has never been more important to ensure that we develop inclusive, resilient communities and economies where health truly is factored into everything we do.

We know that some individuals with protected characteristics face actual or perceived discrimination when accessing services resulting in unmet health needs and the newly established NHS Health Inequalities Group is working to maximise the impact of the NHS in Wales in tackling health inequalities. The Group's work programme is seeking to add value to existing work programmes, strengthen collaborations, avoid duplication, scale up good practice and seek to fill gaps where necessary.

Other examples of work to tackle health inequalities includes:

- Wider cross-government action such as the [Flying Start](#) programme, action to tackle poor quality housing and fuel poverty, our Employability Plan and efforts to tackle air pollution.
- The Socio-economic duty requires specified public bodies to consider how their decisions might help to reduce the inequalities associated with socio-economic disadvantage when making strategic decisions such as 'deciding priorities and setting objectives'.

- Welsh Government [guidance](#) for Health Boards on Health and Wellbeing Provision for Asylum Seekers and Refugees (2018) has also been issued which includes a specific focus on chronic conditions. It recognises that the most frequent health problems of newly arrived refugees and asylum seekers include accidental injuries, hypothermia, burns, gastrointestinal illnesses, cardiovascular events, pregnancy and delivery-related complications, diabetes and hypertension, all of which can lead to more chronic conditions requiring long-term treatment.
- In addition Welsh Government [guidance](#) for Healthcare Practitioners on Working Effectively with Gypsies and Travellers (2015) also recognises the high prevalence of chronic ill health amongst Gypsy, Roma and Traveller communities, such as cardio-vascular disease, cancers, diabetes asthma and other respiratory conditions, as well as higher rates of stroke, and poorer mental health outcomes.

One of the principles underpinning the Welsh Government's draft Mental Health and Wellbeing Strategy (currently out to consultation – see [below](#)) is equity of access, experience and outcomes without discrimination and ensuring services and support are accessible and appropriate for all. This means understanding the barriers people face and putting necessary systems in place so that when people get support, there is equity in terms of experiences and outcomes.

To achieve this, support and services will need to be culturally and age appropriate and meet the needs of Welsh speakers, ethnic minority people, LGBTQ+ communities and people with sensory loss. Services will also need to meet the needs of under-served groups such as people with co-occurring substance misuse, people who are care experienced, neurodivergent people and people who are experiencing poverty and people who are experiencing homelessness.

Welsh Government is also committed to embedding the Social Model of Disability throughout everything it does. A Disability Rights Taskforce has been established, which brings together people with lived experience, Welsh Government officials and organisations to identify the issues and barriers affecting the lives of many disabled people.

Additionally, the Welsh Government's Out of Work Peer Mentoring Service (OoWS) helps some of the most vulnerable, and those furthest away from the labour market, to rebuild their lives and to get back into training, education and employment. The service provides free peer mentoring support to people out of work who are recovering from ill-health. Between October 2022 and March 2025, the service will aim to support 10,000 people and potentially improve the health and educational outcomes of children and families living in poverty, where family income improves by gaining employment.

Complementing this is the Welsh Government's In-Work Support Service which provides free and rapid access to occupational support to keep people in work and is essential for reducing ill-health, social exclusion and poverty.

Earlier diagnosis of some long-term conditions, particularly those with risk factors that are modifiable through individual lifestyle changes and public health interventions, will allow better management through those lifestyle changes or more

cost-effective home care. Tackling inequalities in wider determinants like housing, income, education, and employment will also produce health benefits.

Good practice examples of person-centred care for people with multiple conditions which could be mainstreamed into policy and delivery

Integrated Community Care System

An Integrated Care Community System (ICCS) attuned to the care and support needs of people with complex care and support needs is being developed. Older people and people living with frailty is the first population group of focus, underpinned by the [IQS](#). By prioritising community-based care, we aim to support older people to maintain independence and quality of life, while effectively managing healthcare resources.

Adferiad (Recovery) funded services

Welsh Government is investing £8.3m per annum in the [Adferiad \(Recovery\) funded service model](#). Initially established to support those with long COVID as a part of our response to the pandemic, this is a community focussed multidisciplinary and blended rehabilitation and recovery approach, which includes self-management and supported self-management strategies, as well as referral pathways to specialist secondary care for those who need it. In 2023, access to these services was widened to people with a range of other long-term conditions but similar recovery and rehabilitation needs to those with long COVID. The increased and ongoing funding is to enable capacity in primary and community care to be expanded to continue to support people with long Covid whilst also creating equitable access to others on a 'needs led' and 'symptom led' basis, for example, people with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), fibromyalgia, persistent unexplained symptoms and other post-infection associated conditions. Many people accessing these services will have multiple long-term conditions requiring multidisciplinary and co-ordinated care and support to maximise quality-of-life outcomes.

Health and Wellbeing

Cardiff [Keeping Me Well](#) website is designed by health professionals who specialise in different therapy services and service users from Cardiff and Vale University Health Board. The information on this website helps people support their health and wellbeing — whether they are preparing for treatment, recovering from treatment, managing a long-term condition or looking to live a healthier and more active lifestyle.

The Cwm Taf Morgannwg University Health Board's older persons mental health team is a multi-professional team providing assessment and treatment by psychologists, medics, mental health nurses and occupational therapists. Each individual has their own care plan. The service respects individuals' rights to exercise control over their own lives, care and ability to make choices in an informed and safe way, whilst aiming to promote the values of independence, choice and empowerment for service users.

Cardiovascular Disease Prevention Group

The Cardiovascular Disease Prevention Group (CVDPG) has been established under the Cardiovascular Strategic Clinical Network and is being led by Public Health Wales. The CVDPG will focus on a range of primary, secondary and tertiary prevention interventions that address the common factors that increase the risk of cardiac illness, vascular disease and stroke.

In collaboration with Strategic Programme for Primary Care, the Six Goals Programme, clinical and policy leads across stroke, cardiac, vascular and diabetes, and relevant third sector partners, such as the Stroke Association, the CVDPG will maintain a focus on **A**trial Fibrillation and **B**lood Pressure management (Hypertension) in the first instance, with plans for focussed activity relating to **C**holesterol and **D**iabetes (the ABCD).

This is a good example of how bringing a family of networks together is facilitating collaborative working across partners towards a common goal to improve population outcomes for people with different conditions.

Children's Continuing Care

Welsh Government published revised guidance on [children's continuing care](#) in early 2020 to guide NHS Wales and partners in supporting children and young people with complex health needs.

The continuing care guidance for Wales describes the interagency process, led by health boards, that all organisations should implement in assessing needs and putting in place bespoke packages of continuing care for those children and young people who require it because their needs cannot be met by existing universal or specialist services alone.

The children's continuing care guidance emphasises throughout that the child's needs should be paramount and that any discussions around the financial aspects of providing care should not delay the provision of that care.

National Exercise Referral Scheme (NERS)

The [National Exercise Referral Scheme](#) (NERS) is a chronic condition prevention and management programme which aims to improve the health and wellbeing of sedentary and inactive adults who are at risk of developing or who have an existing chronic condition. It provides a 16-week programme of physical activity to individuals referred by NHS health professionals, using behaviour change techniques to embed positive physical activity habits.

Once referred, patients that meet the criteria are invited to their local leisure centre for an initial assessment with a qualified exercise referral professional. They will be offered a tailored, supervised exercise programme for 16 weeks and their progress will be reviewed at key points.

Rehabilitation

The Welsh Government published the [All Wales Rehabilitation Framework \(2022\)](#) to support health boards, trusts, local authorities and third sector partners to better understand the increasing demand for rehabilitation, reablement and recovery throughout health and social care services. The Framework presents a stepped care model that ensures the right level of care in the right place by the right professional. It identifies five principles to develop person-centred rehabilitation services that respond to people's needs, including those living with multiple long-term conditions.

Good rehabilitation is based on a thorough professional assessment of the persons abilities and needs to form a person-centred goal-oriented plan. Rehabilitation should be accessible both as a preventative and recovery focussed intervention. This means people can access it early in their care pathway to prevent deterioration and avoid the need to increase care including admissions. It should be available to everybody to ensure their maximum recovery and return to independence after medical intervention. Rehabilitation is an intervention ideally suited for people with multiple and long-term conditions.

The [All-Wales Community Rehabilitation Best Practice Standards](#) were published in September 2023 and should be used by all services across Wales.

There are many examples of innovative AHP services providing direct, early access to intervention, community rehabilitation and reablement and other treatments in the community. Rehabilitation, reablement, intermediate care and recovery (mental health) services should be fundamental elements of every care pathway, but particularly for those with long term health conditions.

Allied Health Professionals (AHPs) are experts in delivering treatments and rehabilitation that is particularly important in supporting the complex needs of people who are frail or living with long-term health conditions. The £5m investment to expand AHPs and support worker posts in Primary and Community Care has already resulted in over 88 new (FTE) posts being made available. Increasing community rehabilitation and community-based therapy ensures people recover their ability and confidence to do the things that matter to them in their daily life, enabling more people to live independently without having to rely on unnecessary long-term social care.

Medicines review

People living with chronic conditions are more likely to be prescribed multiple medications and more likely to experience adverse effects as a result of multiple medications. In Wales, we encourage the prescribing of medicines that offer the best health outcomes improving the quality of life for patients living in Wales. The overall aim of value-based prescribing is to optimise the usage of medicines to deliver increased value. Often this requires input from the multi-disciplinary team, with pharmacists and pharmacy technicians supporting GPs and nurses in their prescribing decisions.

Medicines reviews are an opportunity to provide a person-centred approach and involve people with multiple conditions in shared decision making about their care. Reviews can be undertaken by the healthcare team within the GP surgery or via the Discharge Medicines Review scheme, where a person is referred to their community pharmacy team for a review of their medication following a transfer of care between different settings i.e. hospital to home.

Support required to enable effective self-management of chronic conditions where appropriate, including mental health support

New General Medical Services (GMS) Regulations came into effect on 1 October 2023, underpinning the new Unified Contract and representing the most significant reform of GMS contract since 2004. The Unified Contract simplifies and streamlines what services all GP practices in Wales must provide and how they evidence assurance of delivery.

The 2023 Regulations specify that in managing the care of people with chronic conditions, GPs must take into consideration relevant nationally agreed clinical guidance or pathways, in discussion with the individual. This will help to support a consistent and person-centred approach to care.

A new [Assurance Framework](#) has been developed alongside the new contract. To ensure a focus on quality of care and improving patient outcomes, the Assurance Framework indicators have been mapped to the [Health and Care Quality Standards](#) (2023). Our expectation is that Health Boards will be able to use this Framework to manage their GMS contracts and to monitor local improvement across a range of chronic conditions.

While general practice has a key role to play, people at risk of or living with several long-term health conditions have very individual needs. For effective support, people require access to a range of health and social care professionals working together in a coordinated way through the clusters to help identify these needs and agree with the individual how best to meet those needs, making use of all sources of help. Health boards and local authorities are expected to enable these professionals and services to be organised to work together as a team with the person receiving that care right at the heart of that team and all it plans and delivers.

Through these integrated multi professional teams of GPs, nurses, pharmacists, allied health professionals, social care workers and the third sector, individuals who need support are systematically identified and a care plan is agreed with them with goals and actions to stay well and seek help at the right time in the right way to avoid exacerbations or be responded to at or close to home where urgent care needs do arise.

Mental health

The [draft Mental Health and Wellbeing Strategy](#) is currently out to consultation, closing 11 June. Within the strategy we recognise that there is a need to focus on promoting equity when it comes to people's experiences and outcomes (and not just focus on reducing inequity in terms of access to services and support). We know that people with a long-term physical health condition as are more likely to experience mental health conditions than the general population. We are proposing actions that focus on the physical health needs of people with a severe and enduring mental health condition and increasing access to psychological therapies to those with a long-term physical health condition.

The draft strategy also reflects on the need to embed a trauma informed approach. It recognises that trauma-informed organisations understand that adversity, trauma and distress can occur to anyone and at any point across the life course. They aim to create psychosocially healthy conditions for both the workforce and people they support to minimise exposure to adversity, trauma and distress. They will also be confident in understanding what interventions and supportive factors someone may need in place to prevent and mitigate the long-term impact on physical and mental health and wellbeing.

Within the strategy we also recognise specific needs of supporting those with eating disorders. With funding provided by the Welsh Government, health boards have adapted and expanded services and recruited additional staff. This has enabled easier access for people with eating disorders to specialist services in the community. We have also provided dedicated resources in the new NHS Executive to further support improvements to mental health services, which includes the appointment of a National Clinical Lead for Eating Disorders. Early intervention is vitally important, and the clinical lead is working with Health Boards to implement a new service model of care designed for young people to receive the help they need and to prevent the need for in-hospital care. All health boards continue to make progress to achieving the NICE standards for eating disorders services, earlier intervention and to ensure no one is waiting longer than 4 weeks for an assessment.

The focus on specialist services is only one element of our broader approach. We have continued to dedicate investment in a range of easy to access support including the BEAT Wales helpline and services. This not only helps provide early access and advice but supports many people waiting to be seen by clinicians. We also need to continue our focus on prevention. This includes work in schools about promoting positive body image. We will be looking for further opportunities to strengthen this through our new Mental Health and Wellbeing Strategy.

Allied health professionals

Allied health professionals (AHPs) are essential members of multiprofessional teams, supporting individuals with a range of long-term conditions. Their skills are critical at all points of every pathway and prevent the development and deterioration from the impact of long-term conditions, and their expertise in rehabilitation and recovery enable people to manage their symptoms, maintain their independence and improve their quality of life. For example, the [All-Wales Diabetes Prevention Programme](#) uses the expertise of dietitians to help people make significant life changes with the potential to reverse the development of type 2 diabetes.

The [Allied Health Professions Framework: Looking Forward Together](#) sets the vision for the transformation of AHPs services to meet the challenges of including increased access, a greater proportion of the workforce in primary and community services, and the increase of community rehabilitation. This will provide the whole pathway access required to maximise health outcomes.

Priority actions required to improve prevention and early intervention

First 1000 days

Welsh Government remains committed to the [first 1000 days](#) centres around providing children with the best possible start in life. During this time, the foundations for future health, mental well-being and social developments are laid. Evidence highlights the significance of this early phase, shaping not only individual lives throughout the life course but also impacting on generations to come.

Making Every Contact Count (MECC)

Through our [MECC](#) approach we are aiming to empower staff working particularly in health services, but also partner organisations, to recognise the role they have in promoting healthy lifestyles, supporting behaviour change and contributing to reducing the risk of chronic disease.

This extends not only to their interaction with clients/patients, but also to their own health and wellbeing and that of their friends, families and colleagues. To be successful MECC must not be seen as a separate public health initiative, but a part of what we all do. Adopting this approach will allow us to move to a position where discussion of lifestyle and wellbeing is routine, non-judgemental and integral to everyone's professional and social responsibility.

Primary prevention

Primary prevention remains a key focus of Welsh Government's approach to chronic conditions and the Tobacco Control Strategy and Delivery Plan is a key example. Tobacco remains a leading cause of chronic conditions such as cardiovascular disease, COPD and coronary heart disease. Preventing people from smoking in the first place is a priority for the Welsh Government, as is helping people to stop smoking for good, which is one of the best things that can be done to improve health

and prevent, or reduce the harm from, long term chronic conditions.

In July 2022, we published [A Smoke-free Wales: Our long term Tobacco Control Strategy for Wales](#), which sets out our ambition for Wales to be smoke-free by 2030. It establishes how we will tackle all aspects of smoking. To support the delivery of the strategy, we have put in place a series of two-year delivery plans, the first of which was [published](#) in July 2022. Significant progress has been made since the Strategy and Delivery Plan was launched, as outlined in the first [annual report](#).

Other work in this area includes Welsh Government's involvement the Tobacco and Vapes Bill, working jointly with all four UK nations to develop legislation on smoking and to tackle youth vaping.

Tackling obesity is another of Welsh Government's top priorities in the prevention of chronic conditions in Wales. Obesity is one of the leading causes for chronic poor health, being associated with serious illnesses like heart disease, type 2 diabetes, and a number of cancer types, especially hormone dependent ones, as well as the need for joint replacement. Preventing or treating obesity effectively would certainly reduce avoidable harm.

The [Healthy Weight, Healthy Wales](#) strategy covers a 10-year period (until 2030) in recognition of the long-term systemic changes that need to take place to effectively address the causes of obesity in Wales. Supporting the strategy are five two-yearly delivery plans which provide detail on the actions needed for a whole systems approach to make positive change.

Evidence shows that the best chances of success come from policies which are aimed at the whole population, improving quality of life and environments. Strategies that focus on prevention are more effective because weight maintenance is much easier than weight loss.

Tackling substance misuse (drugs and alcohol) is another method for preventing chronic conditions that is rooted in a harm reduction approach that recognises addiction as a health and care issue as opposed to one that is solely related to criminal justice. We want to ensure that people in Wales are aware of the dangers and the impact of substance misuse, including their contribution to chronic health conditions.

Preventing future substance misuse is as important as treating the established problem and we aspire to a position where no-one in Wales is ignorant to the consequences of misusing drugs or alcohol, or about where they can seek help and support.

We have protected and increased funding for our frontline substance misuse services, which has risen this year to over £67m, with a further £2m allocated directly to our substance misuse Area Planning Boards who commission services in their areas. Current areas of focus are: the distribution of Naloxone; the national implementation of injectable buprenorphine (Buvidal); continued work with our Area Planning Boards to ensure a range of services and support is in place to support people who are experiencing alcohol problems; the introduction of a minimum unit price (MUP) for alcohol which will help reduce alcohol related harm and support

people to drink responsibly.

Another means of prevention of chronic conditions that Welsh Government employs are the national population screening programmes recommended by the National Screening Committee. These cover all ages, from pregnancy, maternity and newborn, through school age vision and hearing, and adult cancer screening programmes. Population screening programmes in place for breast, bowel and cervix contribute to improving cancer outcomes through early diagnosis and treatment, reflecting one of the Welsh Government's top priorities. Public Health Wales is scoping how a targeted lung cancer screening programme could be delivered, in line with the recent NSC recommendation for a targeted programme.

Cardiovascular screening is also offered through the National Screening Committee recommended [Wales Abdominal Aortic Aneurysm Screening Programme](#) (WAAASP). Men aged 65 are invited for a one-off screen to look for swelling in the aorta. The aim of the programme is to identify and treat AAAs early, reducing the number of ruptured AAA and deaths in Wales.

The [Diabetic Eye Screening Wales](#) programme looks for diabetic eye disease in people aged 12 and over who have been diagnosed with diabetes. Diabetic eye screening can find changes in the eyes before it affects eyesight. Finding changes early and having treatment can prevent sight loss.

The [HIV Action Plan for Wales 2023-26](#) contains 30 actions aimed at achieving the World Health Organization's goal of zero new HIV infections by 2030. The actions are focussed on five key areas: prevention; testing; clinical care; living well with HIV and tackling HIV-related stigma.

These programmes are a good example of effective equitable preventative health interventions as they are offered to all the eligible population across Wales.

Welsh Government is working to expand primary and community multiprofessional teams, e.g. community resource teams, mental health teams and dementia services, and make them more equitably available across Wales as part of the community infrastructure programme.

Secondary prevention

The Welsh Government secondary prevention approach to chronic conditions includes focusing on the avoidance of complications of chronic disease through patient empowerment and good chronic condition management.

In August last year, the Welsh Government announced the '3Ps' Policy, [Promote, prevent and prepare for planned care](#), in line with the commitments made in the Planned Care Recovery and Transformation Plan to better support and inform people with long-term conditions and those waiting for planned care in Wales.

We have invested just under £6million this year to support health boards to deliver on this commitment by establishing a single point of contact within each health board where people, based on their individual care needs, can access advice, support and be connected to their local community assets.

This model, combined with supported self-management, enables and empowers individuals to become more confident partners in their care and to better self-manage their condition through specialist information, advice and education programmes.

Social prescribing is another area which Welsh Government is focusing on, as it can help manage a person's chronic condition to avoid complications. Social prescribing is an umbrella term that describes a person-centred approach to connecting people to local community assets. Community assets include community groups, interventions and services which could be delivered online or in person, as well as buildings, land or even a person within a community.

It recognises that the health of people is determined by a range of social, economic and environmental factors; supporting people to take greater control of their own health and supporting the broader preventative agenda. It is also seen by many as a mechanism to help address issues in relation to loneliness and isolation, promote well-being and to prevent the development of non-communicable diseases.

As outlined within our Programme for Government, we are committed to developing a [National Framework for Social Prescribing](#) which delivers a vision of social prescribing in Wales that is of a consistent high-quality standard across the country.

Russell George MS
Chair, Health and Social Care Committee

Mike Hedges MS
Chair, Legislation, Justice and Constitution Committee

10 June 2024

Dear Russell and Mike,

Health and Social Care (Wales) Bill: legislative competence and human rights considerations

In accordance with section 110(3) of the Government of Wales Act 2006 (the 2006 Act) and Standing Order 26.4, I have laid a statement setting out my view on whether the provisions of the Health and Social Care (Wales) Bill would be within the Senedd's legislative competence.

It is my view that one of the provisions of the Bill, paragraph 4 of Schedule 2, would not be within legislative competence as it requires Minister of the Crown consent, and such consent has not been received at the time of introduction. My statement on legislative competence reflects this position.

As Members will be aware, while I am required to make a statement setting out my views, the content of my statement does not affect whether or not a Bill may be introduced or complete its passage through the Senedd.

I have also considered the compatibility of the provisions in the Bill with the rights set out in the European Convention on Human Rights ("ECHR"). Whilst my overall conclusion is that the provisions in the Bill are compatible with the ECHR, my view is that the position in relation to

certain provisions is finely balanced, with persuasive arguments both for and against compatibility. As such, I believe these provisions would merit scrutiny by the responsible committees during Stage 1.

To help inform this work, I enclose a summary of the human rights considerations that are relevant to the Bill. If you would like further information and advice, the officials supporting the Committee will be pleased to assist.

I am copying this letter to the First Minister, the Minister for Social Care (as the Member in charge of the Bill) and all Members of the Senedd.

Yours sincerely,

A handwritten signature in blue ink that reads "Elin Jones".

The Rt. Hon. Elin Jones MS/AS

Llywydd

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

Human Rights considerations relevant to the Bill

1. Careful consideration should be given as to whether any provisions of the Bill engage any rights under the European Convention on Human Rights ("ECHR"), but particular consideration should be given to **Article 8 and Article 1 of the First Protocol to the ECHR**. The Explanatory Memorandum to the Bill makes no reference to the Welsh Government's views on the potential human rights impact of the Bill.

Article 8

2. Article 8 of the ECHR states:

Everyone has the right to respect for his private and family life, his home and correspondence.

There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

3. Committees may wish to carefully consider the impact of the following sections of the Bill:
 - **Section 4** inserts a new Schedule 1A into the Regulation and Inspection of Social Care (Wales) Act 2016 ("the 2016 Act"), providing for transitional arrangements for registration as a provider of restricted children's services. Schedule 1A will allow the Welsh Ministers to, by regulations, set a date by which existing profit-making providers of restricted children's services must become non-profit-making, or no longer be registered. Article 8 may be engaged if service providers cease their provision of the service when they are no longer able to make a profit, which would have an impact on the rights of children who are cared for by such providers.
 - **Section 13** inserts new provisions into the Social Services and Well-being (Wales) Act 2014 ("the 2014 Act") to permit "supplementary placements" to be authorised by the Welsh Ministers, where a child may still be placed with a for-profit provider if the local authority decides that is the most appropriate placement and there is no not-for-profit alternative available. Again, this would have an impact on the rights of the children who require the placement.
 - **Section 10** of the Bill amends section 75 of the 2014 Act. Section 75, as currently drafted, provides that a local authority has a general duty to take steps to secure, as far as reasonably practicable, that it is able to provide certain looked after children with accommodation within the local authority's area. The amendment which section 10 seeks to make will mean that local authorities must take all reasonable steps to secure that such accommodation can be provided within or near to the local authority's area. This means that placements that are available to a local authority may be outside of its area. The Explanatory Note to section 10 notes there will be circumstances in which a child placed outside of a local authority's area may be nearer to their home community than if they were placed in a different part of the local authority's area, but this amendment could also result in children being placed further away from their home community. The purpose of section 10 is set out in the Explanatory Notes as to enable local authorities to

make arrangements with each other to develop new children's homes and foster care placements. The Explanatory Memorandum also states that, wherever possible, the Welsh Government wants to see placements provided for children and young people that will preserve their links with their local neighbourhoods and communities and allow as much continuity in their lives as possible.

Article 1 of the First Protocol ("A1P1")

4. A1P1 states as follows –

Every natural or legal person is entitled to the peaceful enjoyment of his possessions. No one shall be deprived of his possessions except in the public interest and subject to the conditions provided for by law and by the general principles of international law. The preceding provisions shall not, however, in any way impair the right of a State to enforce such laws as it deems necessary to control the use of property in accordance with the general interest or to secure the payment of taxes or other contributions or penalties.

5. Committees may wish to carefully consider the impact of the following sections of the Bill:

- **Section 3** inserts a new section 6A into the 2016 Act, which imposes a requirement that children's care home services, fostering services and secure accommodation services be not-for-profit in order to be registered to provide restricted children's services.
- **Section 4** imposes a similar requirement on a transitional basis to existing providers of restricted children's services.
- **Section 8** amends the 2016 Act to make reference to the requirements set out in the proposed new section 6A when an application is being made to vary an existing registration to add the provision of restricted children's services.

6. Any provision that deprives an individual of their property will potentially engage A1P1. A1P1 says that every person "is entitled to the peaceful enjoyment of their possessions. No one shall be deprived of their possessions except in the public interest and subject to the conditions provided by law."

7. The concept of possessions is very broadly interpreted in the case-law of the European Court of Human Rights. It is not confined to physical possessions and can include profit, although it has not been interpreted to mean future earnings.

- **Sections 4(4) and 4(5)** of the Bill amend the 2016 Act so that the Welsh Ministers may prescribe by regulations that it is an offence for a provider to fail to comply with conditions imposed in regulations made under the new Schedule 1A to the 2016 Act. Such an offence is punishable by a fine or a fixed penalty notice.

- Similarly, **section 14(3)** of the Bill makes it an offence to fail to submit or publish an annual return within the prescribed time limit, and a person guilty of such an offence is liable on summary conviction to a fine.
8. The issue of a fine engages A1P1, but deprivation of property is permissible where the policy is: justified on grounds of public interest, proportionate to the public interest aim pursued, done in accordance with domestic and international law and has legal certainty..

Supporting people with chronic conditions

Engagement findings

June 2024

As part of the Health and Social Care Committee's inquiry into *supporting people with chronic conditions*, the Citizen Engagement Team proposed a qualitative approach to engagement, comprising a series of interviews and focus groups with people across Wales with lived experience of chronic conditions. This paper communicates the findings of those interviews and focus groups.



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1. Background

1. The Health and Social Care Committee are holding an inquiry into supporting people with chronic conditions. The Committee wanted to identify practical actions on how to deliver the vision of holistic, person-centred care for the growing number of people living with chronic conditions and consider what needs to change to improve people's experiences and outcomes.
2. The Committee were interested in hearing the lived experiences of people living with chronic conditions and how best to enable services to focus on the person as a whole, not their individual conditions.

Engagement

3. Between 1 December 2023 and 26 March 2024, the Citizen Engagement Team facilitated 31 individual interviews and three focus groups with a total of 56 people (45 female and 11 male) living with chronic conditions.
4. The purpose of the engagement was to provide the Committee with the views of people living with chronic conditions, on how best to implement person-centred care for people with chronic conditions, based upon their own experiences.

Participants

5. Participants were sourced via a screening survey sent to over 25 organisations and support groups relating to various chronic conditions.
6. The Citizen Engagement Team worked in collaboration with organisations and charities to identify some participants.¹
7. All participants either live with chronic conditions or care for people with chronic conditions. Many of the participants live with multimorbidity (two or more chronic conditions).
8. Many of the participants either have worked or are currently working within the NHS in Wales, or their chosen field of work relates to the healthcare service.

¹ See Annex 1

9. Over 20 different chronic conditions were represented in the engagement sessions.²
10. The ages of the participants ranged from early twenties to late seventies.
11. Participants came from all seven health boards and 14 of the Local Authority areas across Wales.
12. Thank you to everyone who contributed to the programme of engagement, especially the participants, who shared their experiences.

Methodology

13. Engagement was conducted both online and face-to-face, according to the preference of the participants.
14. The following discussion points were addressed during the programme of engagement:
 - a. What are the positives and/or negatives you've experienced while accessing support/treatment for chronic/long-term conditions?
 - b. What are the main barriers, if any, you've faced whilst accessing support/treatment for chronic conditions/multiple conditions?
 - c. What would have made/would make the biggest differences/improvements to your experience of accessing support/treatment? (What things/actions/policies do you think would help you and others with chronic conditions the most?)
 - d. What, (if anything) do you think needs to change in health and care services to better meet the needs of people with chronic conditions?
 - e. What practical actions do you think would help to improve person-centred care, particularly for people with multiple conditions? (so that support and treatment are designed around the person as a whole, not just individual conditions or symptoms in isolation)

² See Annex 2

- f. Do you feel you've been given enough support to enable effective self-management of your condition(s)? For example, mental health support. If not, what additional support is needed?
- g. In your view, how can prevention and early intervention in chronic conditions be improved? Where should efforts be focused?
- h. Have you come across any good practice examples of person-centred care for people with multiple conditions?

2. Executive summary

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<p>Person-centred care</p> <p>The engagement findings underscore the need for person-centred care for individuals with chronic conditions, emphasizing patient involvement and strategic mindset shifts. Participants advocate for patient forums and co-production in healthcare decision-making, distinguishing between raising concerns and filing complaints with separate policies.</p> <p>Practical solutions proposed include dedicated phone lines for chronic condition patients, quiet A&E waiting areas, and direct medication collection from hospital pharmacies. Emphasis is placed on the necessity of face-to-face appointments and patient-initiated follow-ups, urging healthcare professionals to treat patients as individuals rather than merely symptoms. Recommendations include multidisciplinary annual reviews and a 'super team' approach for co-ordinated care.</p>	9
<p>Dismissed by medical and healthcare professionals</p> <p>Many participants report feeling dismissed by healthcare professionals, negatively impacting their physical and mental health. They recount not being listened to and questioning their judgment due to dismissive comments. Positive interactions, however, highlight the importance of empathetic communication from healthcare providers.</p>	15
<p>Training and refresher courses for medical and healthcare professionals</p> <p>Participants acknowledge excellent services but stress the need for continuous training and refresher courses for healthcare professionals. Training should focus on patient care, empathy, and understanding of chronic conditions, particularly dementia. Addressing "medical misogyny" and improving communication with neurodiverse patients and those with learning difficulties is</p>	16

THEMES	PAGE
crucial. Follow-ups to help healthcare professionals learn from missed diagnoses were suggested.	
<p>Communication</p> <p>Improved communication across healthcare levels is critical. Participants describe challenges with communication between health boards, specialists, and departments, advocating for shared patient notes to streamline care. Clear communication about conditions and treatment options is essential for effective patient care.</p>	18
<p>‘The GP barrier’</p> <p>Participants highlight varying quality in GP practices. Suggestions include empowering GPs to refer patients directly to specialists, recognizing the frequent healthcare needs of chronic condition patients without guilt, and ensuring consistency in care. A red flag system to identify chronic condition patients and better use of ICT, including an accessible patient notes portal, were recommended. Longer GP appointments to discuss multiple related conditions are seen as crucial for comprehensive care.</p>	19
<p>Diagnosis</p> <p>Experiences with diagnosis varied significantly. Some participants reported timely diagnoses and early intervention, while others faced delays of 10 to 25 years for conditions like endometriosis and fibromyalgia. Misdiagnoses were also an issue. The need for a holistic, person-centred approach following diagnosis is highlighted.</p>	21
<p>Lack of specialists</p> <p>There is a notable shortage of specialists for chronic conditions in Wales, impacting care quality. Participants reported seeking private treatment or travelling outside Wales due to local expertise unavailability. The suggestion of a specialist consultant role for chronic conditions was made to bridge this gap.</p>	22
<p>Lack of consistent quality of care, Wales-wide</p> <p>The quality of care across Wales is inconsistent, with rural areas particularly disadvantaged. Participants expressed concerns about inadequate provision influencing their living decisions. Travel challenges and limited public transport deter some from seeking necessary medical attention, worsening their conditions.</p>	23
<p>Mental health support</p> <p>The correlation between chronic conditions and mental health needs is significant, yet often overlooked. Participants highlighted</p>	23

THEMES	PAGE
difficulties in accessing mental health support. A holistic approach addressing psychological alongside physical needs is essential.	
Benefit of charities and support groups Charities and support groups provide crucial support and information. Participants valued the opportunity to share experiences and learn from others. Increased awareness and signposting to these groups at diagnosis could alleviate feelings of loneliness and improve well-being.	25
Support for carers Carers, particularly unpaid ones, require more recognition and support. Their presence at medical appointments should be acknowledged, and they need both practical and mental health support. Ensuring carers receive adequate support will improve care for individuals with chronic conditions and the well-being of the carers themselves.	26
Prevention and intervention Prevention strategies should include early diagnosis and intervention, improving patient outcomes and reducing NHS costs. Screening services should be expanded, and public education on healthy lifestyles enhanced. Increased resources for research and public awareness campaigns can reduce stigma and improve empathy towards those living with chronic conditions.	26

3. Recommendations

15. Participants suggested ways of improving person-centred, holistic care for people with chronic conditions.

Recommendation 1. Further use of patient forums and co-production; service users and carers need to be involved in the decision-making for better healthcare services.

Recommendation 2. Develop continuous, updated training for medical and healthcare professionals on patient communication and care.

Recommendation 3. Establish a chronic conditions information-sharing hub for GPs.

Recommendation 4. Develop an NHS online hub to enable medical and healthcare professionals to access patient notes, from all relevant healthcare services.

Recommendation 5. A multidisciplinary annual review for people with chronic conditions. The review should consider all aspects of the participant's medical, psychological and social needs.

Recommendation 6. Multidisciplinary appointments for people with chronic conditions, where possible.

Recommendation 7. Increase the number of specialist nurses for chronic conditions, especially when there are no consultants for the chronic condition(s).

Recommendation 8. Signposting to psychological support, upon diagnosis.

Recommendation 9. Establish a single point of contact, such as a co-ordinator or hub, to co-ordinate and navigate patient care for people with chronic conditions. This could be used by people with chronic conditions to consult, and seek advice and information on their chronic conditions.

Recommendation 10. NHS telephone line dedicated to people with chronic conditions, allowing immediate access to a medical professional.

Recommendation 11. Allow extended GP appointments for people with chronic conditions.

Recommendation 12. A flagging system to identify people with chronic conditions and enable them to be seen by a GP or referred as soon as possible

Recommendation 13. Offer safe spaces or quiet rooms in A&E departments for vulnerable people and people with chronic conditions.

Recommendation 14. Allowing people with chronic conditions to collect their prescribed medication from hospital pharmacies.

Recommendation 15. People with chronic conditions should be exempt from needing to apply for a blue badge.

Recommendation 16. Further research to identify people who are at risk of developing chronic conditions.

Recommendation 17. Further screening services to identify people who are at risk of developing chronic conditions.

Recommendation 18. Training courses on chronic conditions for people working in various fields, for example, retail and business.

Recommendation 19. Research and audit of support available to carers living with chronic conditions.

Recommendation 20. The Welsh Government should implement the social model of disability across the NHS in Wales.

4. Key themes

Person-centred care

16. All the participants who took part in the engagement spoke about the need for better person-centred care for people living with chronic conditions.

17. Some participants noted the need for further use of patient forums and co-production, in order to better healthcare services and provide a viable person-centred care. Service users and carers need to be involved in the decision making.

18. One participant mentioned the difference between raising a concern within the healthcare service and raising a complaint. There should be two different, separate policies. The participant would like to raise her concerns, but not necessarily make a complaint.

19. Some participants noted the need for a shift in mindset, on a strategic level.

"I've seen it on both sides. What needs to change and I know it sounds simplistic, and I know it isn't, is the mindset...they never take any time to just stand back....and think, what's going to make the patient experience better. It's a fundamental shift in the mindset."

"Decisions aren't being made with patients in mind. They are an absolute breach of all the duties, all the principles, all the values that"

are supposed to be operating on and the patients are not put at the centre....It's so easy to forget about the women in pain."

"Where they [NHS] fall down is with long term conditions.....because it's a drain on resources and there's no instant win."

- 20.** One participant suggested the Welsh Government should implement the social model of disability across the NHS. This empowering social model would encourage co-production to achieve a more positive outlook and a service that would benefit all.
- 21.** Other participants suggested practical solutions to improve procedures and person-centred care for people with chronic conditions. For example, rather than using the 111 telephone service, having a telephone line dedicated to people with chronic conditions, allowing them immediate access to a medical professional.
- 22.** Another participant shared her experience of having appointments cancelled and then being placed at the bottom of the waiting list, rather than change everyone's appointment to accommodate for the cancellations. As a result, the next patient becomes the last.
- 23.** Other practical solutions to improve person-centred care could include A&E departments having a quiet waiting room for vulnerable people and people living with chronic conditions.
- 24.** Some participants mentioned the challenges of medications being contracted to be manufactured by external providers. The participant gave one example of a six week delay in her receiving her medications due to the sharing of inaccurate information with the external provider.
- 25.** One participant suggested allowing people with chronic conditions to collect their prescribed medication from hospital pharmacies.
- 26.** All participants spoke about the need for face-to-face appointments and the opportunity to talk about their chronic conditions and discuss possible options, allowing the patient (and/or carer) to be a part of the conversation, where possible. This is at the heart of person-centred care and in the long term, will lead to more sustainable and far more effective person-centred care.

"Sometimes, you need a face-to-face appointment, and you shouldn't have to beg for that."

"Where they [NHS] fall down is with long term conditions - because it's a drain on resources and there's no instant win."

27. One participant spoke about the pros and cons of patient initiated follow up appointments, where patients are seen as and when they need to be seen by healthcare professionals.

28. Participants noted the importance of treating people living with chronic conditions as individuals.

"You get the impression sometimes that medics are interested in your condition and not necessarily interested in you.....I am a person, not a collection of symptoms."

"[Doctors] are brilliantly clinically trained in the majority of cases but when they come to a patient, they're looking at their notes, they're absorbing the clinical aspects of the individual, but they're not actually looking at the person."

"The specialists just think about the impact it's having on the brain in terms of the seizures. But I think there should be more consideration of the impact on all aspects of a person's life, work, and mental health."

29. Many participants shared their experiences of having no follow-up care, following diagnosis. Having such check-ins would greatly improve person-centred care.

30. Some participants gave examples of being told they would be referred to pain clinics, but still haven't heard anything for over twelve months. One participant mentioned that she waited four years to be referred to the pain clinic.

"The consultant said. 'All the things I was going suggest for you, you've already done yourself.' I said, 'Well, I've been waiting four years. I couldn't wait for you to tell me, what about this and have you thought to try this?' I have got to the stage where I thought I'm going to have to help myself."

31. Participants suggested a multidisciplinary annual review considering all aspects of the participant's medical, psychological and social needs. This might help restore people's confidence in their own ability.

"We have a group of people who won't be able to meet the standards of the healthy population, but they are still a part of society and we need the flexibility of offering the possibility of education, the possibility of jobs or doing something to give value to society."

32. One participant gave an example (pre-Covid 19) of what she described as a 'super team approach'. This involved appointments with several different disciplines and departments and felt listened and treated as a *"whole individual."*

33. Another participant suggested that adult medical care would gain a lot from taking the multi-agency approach often taken in paediatrics, noting that the role of the paediatrician in child medical services could be implemented in adult medical services for people with chronic conditions, particularly people with multimorbidity.

"In the transition process from children to adults almost always....the quality of care goes down."

34. Many participants spoke about the benefits of having specialist nurses but noted the pressures on the specialist nurses themselves, as there are so few of them.

35. Some young participants living with autoimmune conditions feel that the rheumatology departments don't cater for their age range.

36. Many participants spoke of the embarrassment of having to seek help, for example, for financial support, due to either losing their job or being unable to work, as a result of their chronic condition(s).

"I'm feeling uncomfortable with the fact that I've been thrust, due to my health, into a situation I never expected to be in.....There needs to be a one stop shop on financial support."

37. Social intervention is an essential aspect of person-centred care for people with chronic conditions. Patients living with chronic conditions should not need to re-apply for support of all kinds, for example, Personal Independence Plan (PIP) and the blue badge; this causes unnecessary stress.

38. There should be the same responsibility for health and social care within the NHS for people with chronic conditions, and for NHS patients, in general.

"It would be nice to have a joined up health and social care strategy for Wales... We need to put more respect into it."

39. Some participants noted that many people with chronic conditions are having to stay in hospitals when they don't need to be there. This is having a substantial impact on other areas of the health service too.

40. Participants suggested re-introducing cottage hospitals in each health board. This would help to facilitate discharge from hospitals

41. Some participants noted the impact of the decline of district nurses - an invaluable point of contact when considering a more holistic approach to healthcare service.

42. Other participants suggested a return in the practice of home visits which would aid person-centred care, especially for people with chronic conditions who go 'under the radar' if they are too ill to attend hospital appointments.

43. Many participants suggested a co-ordinator or hub – a single point of contact – whereby people with chronic conditions could consult for information and advice. This would improve their confidence and experience of living with chronic condition(s) as well as relieve some of the pressures on primary care appointments. This could be an opportunity to respond to certain issues, raised by specialists, but not necessarily their area of expertise.

"It would be good to have someone dedicated to co-ordinate medical conversations, look at the whole picture and give the patient plenty of time."

"Nobody sees or has any oversight of your journey....I'm just thinking, how are you co-ordinating care for people?"

"It's the patient who's required to join the dots, and to do the work to join the dots. That's not person-centre [care]."

"For anyone who's got any complex health needs and particularly multiple health needs, having a central point of coordination is just logical to me."

- 44.** Participants suggested that there should be far more support for people with chronic conditions, to live with the condition(s) and stay as well as possible, rather than blame them for their health issues. For example, some medications lead to weight gain, and yet they are told to try and lose weight.
- 45.** One participant suggested the need for a similar organisation to SNAP Cymru, to support and advocate for people with chronic conditions. (SNAP Cymru is a national charity offering advice and advocacy for children and young people with additional learning needs and disabilities.)
- 46.** Similarly, another participant suggested adopting a policy similar in principle to Allied Health Professionals (AHP) to co-ordinate and navigate patient care for people living with dementia. This policy could be adapted for other chronic conditions.
- 47.** Participants suggested the current NHS model is *"too medically orientated"* and effective person-centred care should consider prescribing other ways of

supporting people with chronic conditions, for example, attending classes at the local community centre.

48. Many participants spoke about the impact of their chronic condition(s) on their families too and that their need for support needs to be acknowledged too, as part of person-centred care.

Dismissed by medical and healthcare professionals

49. Many participants shared their experiences of not being listened to, by medical and healthcare professionals, feeling that their lived experience has or is dismissed and not being taken seriously. This has had a damaging impact on many of them.

"I went through seven or eight years of doctors turning me away, calling me dramatic and saying I was attention seeking. That was very damaging for my physical or mental health."

"I do wonder whether he'd [GP] listened to me sooner, whether the condition I now have, could have been stopped or made less bad."

50. Some participants spoke of the positive and negative impact of their medical and healthcare professionals' attitudes towards chronic conditions, on them as patients.

"He [doctor] said to me, 'I don't know how you've been doing this for so long'. Hearing that is amazing, when you've heard the complete opposite for so many years."

"I had a doctor once tell me he didn't enjoy doing endo surgery, because the outcome is never good...it's a chronic condition and can't be cured. But, surely, the point of being a doctor is to help people and give quality of life."

"...if they had taken it seriously when I first went, we possibly could have avoided me being in a situation of secondary breast cancer."

51. Many participants shared their experiences of doubting their judgement at times, prior to diagnosis, due to some medical and healthcare professionals' comments.

"She [consultant] was so dismissive and made me feel like I was stupid. It was horrible...[She said]it would be a complete waste of NHS money to operate on me....I would love to message her now and say, 'this is what was missed.'"

52. Another participant gave an example of her GP telling her that they "could spend a fortune testing you for things but you're not dead yet, are you?"

Training and refresher courses for medical and healthcare professionals

53. Participants gave some examples of excellent, "second to none" medical and healthcare services, on all levels.

54. However, participants also noted the need for updated training and refresher courses for medical and healthcare professionals, particularly regarding patient care.

"I think we need to put care back into hospital treatment, which is something which is going to require retraining, because although it's happening with new recruits, we've got existing recruits that haven't had that training."

55. Participants spoke about the need for empathy and a better understanding when medical and healthcare professionals are addressing people with chronic conditions, for example, dementia. This would improve the experience of the patient and address the lack of confidence among some medical and healthcare professionals when dealing with people with chronic conditions.

"There's one thing that's very difficult when you've got a diagnosis of dementia and you're already in an early stage like myself, and people assume you're at late stage and you don't understand anything.....the medical aspect of dementia is a journey and it's different for everybody."

"The stroke team were marvellous.....The NHS is great at that. What they're poor at is when people present with things they don't understand." [Participant also lives with dementia.]

56. Many participants mentioned the “*medical misogyny*” they face regularly and discussed the impact of attitudes towards women, among some medical and healthcare professionals.

"Women are the bottom of the list, but what we forget when we put women at the bottom of the list is the impact that that has elsewhere and the long-term effects that that is having on children who are growing up with things normalised for them. That shouldn't be."

57. Some participants noted the need for specific training for medical and healthcare professionals, when communicating with people with chronic conditions, who are autistic, neurodiverse and/or have learning difficulties.

"He's[one individual in the participant's care] never been tested for epilepsy because the consultant didn't want to do it because he had learning difficulties.....and he told us this, he said it in front of my son."

58. One participant suggested there should be a follow-up with medical and healthcare professionals to highlight and enable them to learn from what they have missed, at the time of consultation or diagnosis.

59. One participant gave a positive example of her GP information sharing with other GPs within the same practice.

“She [GP] is using it [the patient’s experience] as a tool to talk to other GPs and it’s brilliant that she has taken that learning on and keen to help more people.”

Communication

60. Almost all participants spoke about their experiences regarding lack of communication on many different healthcare service levels.

61. To improve person-centred care, all health boards in Wales should be enabled to liaise with each other and share relevant patient notes. Some participants shared the challenges and frustration they face, living within one health board area, but having to receive treatment within one or sometimes two other health boards, yet, there is no communication between health boards.

62. One participant living with multimorbidity, receives support from more than one health board. She explained how she has resolved to keeping her own notes and shares the required information with the different departments during her appointments, due to them not having access to her full medical records.

63. The vast majority of the participants spoke about the need for better communication between different specialists and departments, especially when patients are under several consultants and/or have multiple chronic conditions.

“Some people are qualified to deal with certain aspects of a condition and need to communicate with others so that there is a joined-up thinking about your condition overall. That is particularly the case, I think, when the diagnosis is not an easy one.”

64. Some participants spoke of the impact of the lack of communication between teams and departments on their chronic conditions.

“Slow communication between professionals added to the chronic systemic delays. I feel that if there had been quicker intervention in response to the rheumatologist’s recommendation, my finger ends might have been saved.”

65. Participants mentioned the importance of clear communication by medical professionals, particularly when explaining conditions and options for the patient and/or carer.

“When the neurologist explains things they kind of expect you to know what it is....the information that's being shared with you is not necessarily understandable.”

‘The GP barrier’

66. Some participants spoke highly of their accommodating and supportive local GP practice or medical centre.

“When you’re in with the doctor, you don’t feel like they’re trying to get you out of the room. I’ve always found that there’s been time to ask the questions I want to ask.”

67. Other participants spoke about the need for a clear and well-thought-out medical appointment primary care system, based on the practical and logistical needs of the patient.

68. Many participants spoke of varying degrees of challenges they face liaising with their local GP practice or medical centre.

“It terrifies me just having to contact the doctor.”

69. One participant compared the response rate to her first cancer diagnosis in 2002 – two weeks – to the response rate to her second cancer diagnosis in 2016 – eight months – *“...it couldn’t be more different.”*

70. Some participants suggested the need to empower GPs to be able to refer patients directly to specialists. Currently they are only able to refer to secondary care, who are then able to facilitate a referral to a specialist; processes and protocols need to be reconsidered.

71. Acknowledgement of the needs of people with chronic conditions, including regular or sometimes short-notice appointments to see the local GP was discussed by many participants.

72. Many participants spoke about their 'guilt' of needing to access healthcare services regularly.

"People [with chronic conditions] can't be held accountable for the amount of NHS time they require. It is not something which is deliberate.....they're not hypochondriacs. They have genuine issues which need to be resolved quickly."

73. Participants spoke of their frustration regarding the lack of consistency when seeing their local GP, having to repeatedly explain their chronic condition(s) journey.

74. Many participants noted the challenges of having to telephone to book GP appointments. For example, one participant was told, whilst she was at the local medical centre, that she would have to return home to telephone and book a separate appointment to discuss her blood test results.

75. Other participants also discussed the challenges posed by telephone appointments only, for autistic and neurodivergent people, also living with chronic conditions.

76. Participants discussed the frustration of having to chase appointments and results, regularly, with nobody to advocate on their behalf.

"It's not good enough that in 14 years I've not had a laparoscopy and even worse, how few times I've seen a consultant and it's just not acceptable at all."

77. Some participants suggested ways of identifying people with chronic conditions, when they contact their local GP practice or medical centre. For example, a red flag system to raise awareness of the chronic conditions and enable them to refer the patient as soon as possible. This would also be beneficial for other situations too, for example, sometimes, for various legitimate reasons, people with chronic conditions are not able to attend medical appointments at the last minute.

78. Few participants were able to make appointments and access their medical results via the NHS app. One participant noted the benefit of e-consultations and being able to arrange appointments, blood tests etc. online.

79. However, most participants spoke of the need for further and improved use of ICT to ensure a more effective NHS service, including the use of artificial intelligence to analyse medical tests and scans.

80. Participants noted the need for an accessible portal for patient notes, available to both patient and medical professionals, to ensure better communication, lessen duplication and make sure that things aren't being missed and notes don't get lost.

81. Participants suggested people with chronic conditions should be allocated longer appointments and be allowed to discuss more than one related conditions at a time.

"I know they're [GPs] busy, they haven't got time.....but when things are complicated, it takes time."

Diagnosis

82. Some participants noted their quick diagnosis and early response rate to their chronic condition(s).

83. Other participants with certain chronic conditions, for example endometriosis and fibromyalgia, spoke of the delay in their diagnosis, ranging from 10 to 25 years.

84. Participants with certain chronic conditions, for example endometriosis, spoke about being misdiagnosed, usually with the "dumping diagnosis" of IBS.

85. Another participant spoke about the consequences of her misdiagnosis. She is now living with steroid-induced diabetes (type 2) and hypertension, as a result of being originally diagnosed with giant cell arteritis but then re-diagnosed with fibromyalgia.

86. One participant spoke about how she received her diagnosis, via a text message.

"The doctor texted me to say, 'Hi XXX, your blood test result shows you've got Graves' disease' with absolutely no context. That was quite scary at the time."

87. Some participants spoke of their initial relief in getting their diagnosis and then the struggle to come to terms with living with a life-long chronic condition, with little or no support at the time. A person-centred, holistic approach would have improved their experience, particularly in the early days, following diagnosis.

Lack of specialists

88. Many participants, with a range of different chronic conditions, for example endometriosis, fibromyalgia and scleroderma, spoke about the impact of the lack of specialists for some chronic conditions in the NHS in Wales, on them.

89. Some participants explained how they were told that there was nobody for them to be referred to.

90. Some participants explained how they've chosen to seek private consultation and treatment, usually over the border, due to lack of local expertise. One participant noted she was advised to seek medical healthcare in London.

91. One participant suggested the role of a specialist consultant for chronic conditions. This role could support people with chronic conditions, particularly where there are no specialists, for example, ME and fibromyalgia and could identify the needs of both patients living with chronic conditions and the much-needed support for medical professionals to enable them to offer a more person-centred care.

"Had I stayed with the NHS, I probably would have lost more of my bowel than I already have."

"All the new innovations and new drugs available, we're not party to."

"There are so many chronic conditions and there aren't specialists here in Wales....The GP doesn't have anyone to refer to."

Lack of consistent quality of care, Wales-wide

92. Participants shared their concern about the lack of consistent quality of care across Wales, especially in rural areas, for people with chronic conditions.

“Patients need to have confidence that there will be adequate joined-up provision whichever part of Wales they live in.”

93. Some participants mentioned how this concern was a key factor in their choice of living habitat and others noted that they felt unable to consider living elsewhere in Wales, due to needing to access healthcare services regularly.

94. Participants living in rural areas in Wales noted the challenges and frustration they face travelling to medical and healthcare appointments, due to lack of public transport. This sometimes deters some people with chronic conditions from reaching out for support and/or treatment, leading to devastating consequences.

95. One participant living with epilepsy and unable to drive, noted her one-way three-hour journey on public transport, for a ten-minute appointment.

Mental health support

96. Almost all participants noted the correlation between their chronic condition(s) medical needs and psychological needs, although this is not always acknowledged by medical and healthcare professionals.

“From a patient perspective it feels like at times the psychological impact [of living with a chronic condition] is not understood....I have the best of care when I'm in an acute situation, but once I'm stabilized, there's a massive drop off.”

97. The majority of participants noted the difficulties they had faced accessing mental health support within the NHS, following diagnosis.

“I'm 30. This journey started when I was 13 and I've had 16 operations, multiple organ loss, and it's only now at 30, I'm offered counselling.”

"I only found out psychological support was available, when I cried with the doctor...You've got to be an assertive patient to find out about this stuff, or find it out yourself."

"I'm called XXXX, but I lost a part of XXXX when I was diagnosed, and I had no idea, then, how to get her back."

98. However, some participants commented on the good quality and benefit of the support made available to them, once they had been able to access it.

99. Many participants have sought mental health support themselves and drew attention to the need for flexibility in accessing mental health support as and when needed, bearing in mind that chronic conditions are life-long conditions.

"I don't want to scroll through 100 screens in 50 links. I want to speak to a person and I make no excuses for feeling that way, at the time when I was really low."

"I don't actually like asking for help, but when I do ask for help, it's because I really need it."

100. A more holistic approach to supporting people with chronic conditions should address their psychological needs side by side with their physical needs.

"The impact of trauma on mental health is not necessarily resourced in a joined-up way...There needs to be a more blended approach to rehab."

Benefit of charities and support groups

101. The vast majority of the participants who took part in the engagement, referred to the benefits of charities and support groups and spoke about the positive impact of being able to speak to and share experiences with people living with chronic conditions.

“Although none of these things [support group sessions] are going to cure you, trying to do something positive shifts the mindset.....It would be great if the health boards tried to do something like that as well.”

102. Due to the lack of and/or the need for support groups, many of the participants had either set up or were involved in organising local, face-to-face or regional, online support groups for people living with similar chronic conditions.

103. Some participants noted that their support group was their best and sometimes only source for information sharing about all aspects of living with chronic condition(s) for example, how to access financial support when not able to work.

“I maybe could help people with things that I’ve learnt – from Access to work, from GP referrals, from adaptations you could have to your home – there’s nobody actually telling you about all these things.”

104. Many participants spoke of the need for signposting to, and raising awareness about, charities and support groups, upon diagnosis, describing the loneliness they felt following diagnosis, and often having nobody to advocate for them. This should be a part of an improved holistic approach to supporting people with chronic conditions.

“When you’re not well, to have to fight...when you haven’t got that fight in you.....it’s not fair.”

Support for carers of people with chronic conditions

105. Few of the participants who took part in the engagement were carers for people with chronic conditions, some of them living with their chronic conditions too.

106. Participants noted the need for recognition and support for carers, especially unpaid carers of people with chronic conditions. For example, the presence of carers at medical appointments should be recognised.

“The first thing I always have to do is explain who I am and why I’m there.”

107. Carers of people with chronic conditions, some with chronic conditions of their own, also need practical and mental health support; this is not always recognised.

“Sometimes, I feel very excluded. I feel very lonely, knowing that nobody cares about me...as long as I’m here to do their bidding [individuals in the participant’s care] but that’s affecting my health now and I’m not getting the care for my health because of all my other responsibilities.”

“We need some way of enabling me to take care of myself and to take care of my long-term conditions in a more equitable way...My home is my workplace.”

“We struggle, it’s really hard.....I get worn out by it.”

[advocating for the patient]

Prevention of chronic conditions

108. Participants suggested that prevention starts with listening to the patient and that early diagnosis is key to early intervention.

“If you see specialists in a timely fashion, actually that can end up being both preventative, so improving the patient prognosis, but it can also end up saving money for the NHS because instead of being on that revolving door of repeated less effective interventions, you get to see someone who has a real special interest knows the medical options, knows the treatment options, can supervise more effective care early on.”

109. Acknowledging that it would not be not possible for all chronic conditions, some participants spoke about the importance of developing screening services further, at certain ages, to identify people who are at risk of developing chronic conditions.

110. Other participants spoke about the importance of educating people about healthy lifestyles, concerning the prevention of some, but not all, chronic conditions.

111. Further resources are needed for research and treatments of chronic conditions, including the impact of some chronic conditions on other chronic conditions.

“There needs to be a look at why people develop these chronic conditions other than dementia.....it goes hand in hand....if you’ve got dementia, you’ll get something else. I’m one of them.”

112. Many participants suggested the need to raise awareness among the general public, of the symptoms of many chronic conditions. This would also help reduce the stigma associated with many chronic conditions.

113. One participant suggested the need for awareness training courses on chronic conditions for people working in various fields, for example, retail and business. This too could reduce the stigma associated with many chronic conditions as well as develop empathy towards people living with chronic conditions.

5. Annex 1

Organisations and charities whom the Citizen Engagement Team collaborated with to identify some participants to take part in the engagement:
Alzheimer Society
Breast Cancer Now
British Heart Foundation
Epilepsy Action
Fair Treatment for the Women of Wales
MacMillan
Rare Autoimmune Rheumatic Disease Alliance

6. Annex 2

Chronic conditions represented in the engagement programme
Autoimmune diseases, including scleroderma and lupus
Bilateral Bell's Palsy
Cancer (including breast cancer, leukaemia, melanoma, prostate cancer)
Chronic kidney disease
Chronic blood clotting disease
Coeliac disease
Dementia
Diabetes
Endometriosis
Epilepsy
Fibromyalgia
Graves' disease
Heart conditions (for example, arrhythmogenic cardiomyopathy)
Irritable Bowel Disease (Crohn's and Colitis)
Long Covid
Mental health conditions (short and long term)
Musculoskeletal (MSK) conditions including arthritis
Myalgic encephalomyelitis (Chronic fatigue syndrome / ME)
Respiratory diseases, including asthma
Stroke