Welsh Parliament
**Health and Social Care Committee**

# Supporting people with chronic conditions

January 2025

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# About the Committee

The Committee was established on 23 June 2021. Its remit can be found at:
**www.senedd.wales/SeneddHealth**

## Current Committee membership:

**Committee Chair:**
**Russell George MS**
Welsh Conservatives

**Mabon ap Gwynfor MS**
Plaid Cymru

**James Evans MS**
Welsh Conservatives

**John Griffiths MS**
Welsh Labour

**Lesley Griffiths MS**
Welsh Labour

**Joyce Watson MS**
Welsh Labour

The following Members were also members of the Committee during this inquiry:

**Gareth Davies MS**
Welsh Conservatives

**Mark Drakeford MS**
Welsh Labour

**Sarah Murphy MS**
Welsh Labour

**Sam Rowlands MS**
Welsh Conservatives

**Jack Sargeant MS**
Welsh Labour

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# Chair's foreword

While much attention has been concentrated on acute care, including access to emergency care and waiting times for surgery and urgent treatment, there has been far less focus on the many people who rely on regular access to healthcare to manage one or more chronic conditions.

The Welsh Government's vision is to bring health and social care services together to deliver a person-centred approach, where services wrap around the individual, providing different types of support and treatment in one place. This is far from the experience of those we heard from. Those people described how their conditions are treated in silos, with no patient-centred care and no shared decision making. This is disappointing, as giving patients a voice in their own treatment and the opportunity to express what matters most to them in their care is a vital part of person-centred care.

More broadly, the rising trend in the number of people living with one or more chronic illnesses poses significant challenges to the health and care system in Wales, and the Welsh Government will need to demonstrate strong leadership in order to address this.

Whilst the long-term focus must be on prevention, both to stop chronic conditions developing and to slow their progression, we need to ensure that people currently living with chronic conditions are being properly supported and are receiving the services they need to manage their care. We have made a number of recommendations to try and improve the situation for people living with chronic conditions but ultimately there are long standing, systemic issues with the way health services are currently funded and delivered that need to be resolved before a truly person-centred approach to healthcare can be achieved.

**Russell George MS**
Chair of the Health and Social Care Committee

# Recommendations

**Recommendation 1.** The Welsh Government must take urgent action to ensure a renewed focus on the delivery of person-centred health and care services that are designed around the individual, not their condition. In its response to this report, the Welsh Government should set out the work it is doing to implement its refreshed actions to support its 'A Healthier Wales' strategy. This should include specific milestones for delivery of the refreshed actions, and an assessment of how they will improve care and services for those living with chronic conditions. Page 30

**Recommendation 2.** The Welsh Government should work with health boards to explore reorientating services to 'wrap around' patients living with chronic conditions, providing 'one stop shop' clinics that combine different services and medical professionals in one place. In its response to this report, the Welsh Government should provide details of current work to provide services in this model, and then provide an annual update to us with examples of new services that are being developed. Page 30

**Recommendation 3.** The Welsh Government should review, as a matter of urgency, the use of individual care plans for patients with chronic conditions to ensure that all eligible individuals are offered a plan as a matter of course, and to ensure consistency of practice. It should report back to this Committee with the findings of this review 12 months after the publication of this report. Page 30

**Recommendation 4.** The Welsh Government should set out how it intends to ensure the NHS Executive will monitor and enforce the consistent delivery, by health boards, of the standards for care set out in Quality Statements, and how this will improve the quality of care provided. Page 31

**Recommendation 5.** The Welsh Government should work with the relevant professional bodies and Health Education and Improvement Wales to ensure that continuing medical education opportunities include the perspectives and experiences of patients living with chronic conditions, and promote empathic care. Page 46

**Recommendation 6.** The Welsh Government should work with NHS Wales to improve public understanding of the different roles of members of the multi-disciplinary team in primary care ensure that direct referral services provided by

# 1. Introduction

## Background

**1.** The term 'chronic conditions' (also known as 'long term conditions' or 'longstanding illnesses') includes a broad range of health conditions which often cannot be cured but can be managed with the right support and treatment. Examples include arthritis, asthma, cancer, dementia, diabetes, heart disease, mental health conditions and stroke.

**2.** Many people also live with multimorbidity (two or more chronic conditions). Different groups of people and people from different backgrounds may also experience inequalities in relation to their conditions or their access to services or support.

**3.** According to Public Health Wales, chronic or long-term conditions are experienced by 46 per cent of adults in Wales, with 19 per cent experiencing two or more long-term conditions. The number is predicted to rise[1] and is likely to pose a significant and increasing challenge for health and care services in Wales.

**4.** Some of the predicted increase in chronic conditions is due to an ageing population. The Welsh Government predicts that by 2038, one in four of the population will be over 65 and 13.7 per cent of the population will be over 75, an increase from 9.3 percent in 2018[2]. Age is a key risk factor for a number of chronic conditions, like dementia and some cancers, which makes it likely that we will see an increase in their prevalence. Frailty, which NICE defines as a lack of resilience that means people do not bounce back quickly after illness[3], is also predicted to increase, particularly in the oldest age groups.

**5.** However, people of any age can have a chronic condition. While research has identified that the likelihood of living with multiple conditions increases with age, the number of people under 65 years of age with more than two conditions is higher than the number aged 65 and over. 30 per cent of people with four or more conditions are under 65 years of age[4].

[1] Welsh Government, Report of projections, health evidence and policy recommendations, September 2023
[2] Welsh Government, Report of projections, health evidence and policy recommendations, September 2023
[3] NICE, Improving care and support for people with frailty
[4] Welsh Government, Report of projections, health evidence and policy recommendations, September 2023

**6.** As the then Cabinet Secretary for Health and Social Care[5] told us:

> *"When Aneurin Bevan set up the NHS in 1948, people retired at 65 and men died at 66. That is not the case anymore. People live for a long time. That is testimony to the success of the NHS. But, with that, obviously, comes additional challenges. What we are looking at as a result of that is people living longer, but also living with more complex health conditions."*[6]

## Our inquiry

**7.** The complexity of the issues and the wide range of chronic conditions people may experience prompted the Committee to take a high level approach to this inquiry, to try to find common themes for the improvement of the support for people with chronic conditions, rather than focus on particular conditions. We approached our work in two stages.

**8.** During stage 1, we asked stakeholders to help us by identifying the key themes and issues we should focus on within four broad areas:

- NHS and social care services
- Multiple conditions
- Impact of additional factors
- Prevention and lifestyle

**9.** The responses received provided us with valuable evidence to inform the next stage of the inquiry. A clear overarching message from the consultation was the need to improve person-centred, holistic care, and to stop focusing on individual conditions in isolation for those living with multiple chronic conditions. We therefore agreed the following terms of reference for stage 2 of the inquiry:

- What is required to enable services to better meet the needs of people with multiple conditions (often referred to as "multimorbidity").
- Tackling inequalities and the barriers faced by certain groups, including people living in poverty and people from ethnic minority backgrounds.

[5] Eluned Morgan MS was the Cabinet Secretary for Health and Social Care when we took evidence on this inquiry. She was succeeded by Mark Drakeford MS in August 2024, who was in turn succeeded by Jeremy Miles MS in September 2024
[6] RoP, 19 June 2024, para 6

- Good practice examples of person-centred care for people with multiple conditions which could be mainstreamed into policy and delivery.
- Support required to enable effective self-management of chronic conditions where appropriate, including mental health support.
- Priority actions required to improve prevention and early intervention.

**10.** We gathered evidence in writing, held an informal roundtable discussion with stakeholders and held oral evidence sessions with stakeholders, including the Cabinet Secretary for Health and Social Care (the 'Cabinet Secretary'). Schedules of oral and written evidence are available at Annexes 1 and 2 respectively.

**11.** In addition, our Citizen Engagement Team conducted a series of one-to-one interviews with individuals and families with lived experience[7].

**12.** We are extremely grateful to everyone who contributed to our work.

[7] Supporting people with chronic conditions: Engagement findings, June 2024

# 2. Person-centred care

## Person-centred care

**13.** A Healthier Wales[8], the Welsh Government's long term plan for health and care services, sets out a vision for a person-centred approach to health and social care, where services work with patients "and their loved ones to find out what is best for them and agree how to make those things happen."[9]

**14.** Several witnesses offered a definition of person-centred care as providing services that wrap around the patient, providing different types of support and treatment in one place or integrated service. Professor Jim McManus, Public Health Wales (PHW), told us:

> *"... it starts with the person and looks at what their needs are, sees all of their conditions, not just a condition in silo, and actually works with them to try and do what they can to take charge of their own health, at the same time as actually wrapping around all the necessary services."*[10]

**15.** Zoe Wallace, PHW, said:

> *"If we can reorientate services in a way that we can deliver one-stop shops or integrated services, community-based services, so we're reducing travel times and making it easier for patients and service users to attend clinics, then we are driving down inequalities as well."*[11]

**16.** Participants in our stakeholder roundtable discussion suggested that the system is not set up to provide long-term, person-centred support. Instead, they told us there are short-term interventions before the person is returned to self-managed care, which they cannot always cope with. They said that waiting for these short-term interventions can be demoralising and isolating, telling us that there is a need for long-term support and care packages for people living with chronic conditions.[12]

[8] A Healthier Wales: our Plan for Health and Social Care
[9] In Brief – A Healthier Wales: our Plan for Health and Social Care
[10] RoP, 24 January 2024, para 94
[11] RoP, 24 January 2024, para 90
[12] Supporting people with chronic conditions: stakeholder discussion 28 February 2024

**17.** Participants in our engagement work suggested that a co-ordinator or hub based in each health board could provide a single point of contact for people with chronic conditions to consult for information and advice. They felt this would improve their confidence and experience of living with a chronic condition as well as relieve some of the pressures on primary care appointments.[13]

**18.** They also suggested the introduction of an NHS telephone line dedicated to people with chronic conditions, allowing immediate access to a medical professional.[14]

**19.** According to the Welsh Local Government Association (WLGA):

> *"... there needs to be a shift in focus across the health and social care system as a whole, from health systems centred around hospitals, to health and social care systems focused around communities and community services as defined in their broadest sense. Making community-based care the central focus of the system requires a whole-systems approach to change, spanning hospital services, community services, primary care and social care."*[15]

**20.** It goes on to say:

> *"Transforming the delivery of services is not something that can be achieved overnight and there needs to be realism about the time needed to transform services in the community and to achieve greater alignment with related services such as general practice, mental health, acute services and social care. This shift would also still require additional investment (including a long-term settlement for funding social care) and bringing about the shift from treating conditions to maximising wellbeing requires rethinking how this investment would be used to best effect."*[16]

[13] Supporting people with chronic conditions: Engagement findings, June 2024
[14] Supporting people with chronic conditions: Engagement findings, June 2024
[15] CC47 Welsh Local Government Association
[16] CC47 Welsh Local Government Association

**21.** The Cabinet Secretary acknowledged the importance of treating the whole person:

> *"what we need is to change the way we do medicine to make sure that there's an understanding that you have to treat the whole person. It's not treating one condition; it's about treating the whole person."*[17]

**22.** Dr Stuart Hackwell, Senior Medical Officer for Primary Care and Mental Health, Welsh Government, said that person-centred care was not just about how you structured a service; but was also about how you train healthcare professionals to actually provide that care:

> *"So, a very simple example is someone who comes in with severe osteoarthritis of their knee. Now, the pathway would say, well, at that point you refer on to an orthopaedic surgeon and they have a new knee. Now, if that's not what's important to that patient, and actually what's important to them is to adjust their way of life so they don't need surgery, that is about patient-centred care."*[18]

## Living with multiple chronic conditions

**23.** The number of people living with multiple chronic conditions is predicted to continue to rise, and poses a significant challenge to health and care services, which have often developed to treat single conditions in isolation. In an article in the BMJ in 2020, the Chief Medical Officers (CMOs) of the four nations of the UK said:

> *"The multimorbidity trend presents challenges to the entire medical profession, from general practice and community care to acute and long term hospital settings. Greater specialisation, especially for hospital based doctors, has improved our ability to treat single diseases, but unless we react to the increase in multimorbidity it will disadvantage the increasing proportion of patients with multiple seemingly unrelated diseases."*[19]

**24.** They warned that medical systems, including training in medical schools, clinical teams and clinical guidance, tend to be organised around a single disease

[17] RoP, 19 June 2024, para 7
[18] RoP, 19 June 2024, para 19
[19] Rising to the challenge of multimorbidity, BMJ, January 2020

or organ. This means that a patient may take multiple drugs and see multiple specialists who look at components of their different health conditions, but do not see the overall picture. They write that "there is little or no horizontal integration between diseases that often coexist."

**25.** Dr Frank Atherton, CMO, highlighted the importance of doctors being trained to be sufficiently generalist to meet the needs of those with multiple chronic conditions:

> *"... we have, for a generation now, been training people to be specialists and superspecialists, often, in conditions—and we do need specialist assessment and we do need superspecialist treatment occasionally—but that has been to the detriment, I believe, of general medical knowledge and general medical understanding. And, to really treat multimorbidity and multiple chronic conditions, especially in frail, elderly people, I think you need doctors, clinicians who have a broad understanding of a number of conditions, not just, not solely a detailed understanding of a single condition."*[20]

**26.** The Cabinet Secretary told us:

> *"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. To support this further, the health and care system must also overcome the challenges in the way the workforce is trained and shaped."*[21]

**27.** She further said:

> *"If you look at person-centred care, it has to start in primary care, and GPs are generalists by their nature; they are people who understand the person and the need to look at the whole person. I think, when you get to secondary care, that's where it becomes difficult, because people are specialists. So, we just need to make sure that the specialists also undertake training*

[20] RoP, 17 April 2024, para 141
[21] HSC Committee, 19 June 2024, Paper 1

*and have an understanding of that generalist approach, and, obviously, there are steps being taken towards that."*[22]

**28.** The CMOs of the four nations of the UK recommended that there should be a shift from thinking about multimorbidity as "a random assortment of individual conditions to recognising it as a series of largely predictable clusters of disease in the same person."

**29.** Similarly, Public Health Wales (PHW) told us:

*"Health and care services, which focus on a single condition alone, are often not person-centred, leading to multiple interactions with healthcare professionals, and an inability to consider a person's needs in a holistic way whether the individual is experiencing multi-morbidities/multiple risk factors."*[23]

**30.** This was reflected in the evidence we received from individuals living with multiple chronic conditions. One respondent said:

*"I have literally never been treated in a holistic way. I have multiple conditions that affect the entire body, yet the best I can ever do is see specialists that only handle one small part and then pass me off to someone else".*[24]

**31.** Another told us:

*"Conditions are treated in silos with no patient-centred care and no shared decision making […] I have been given advice for one condition with no recognition that if I follow it, it might make other conditions worse."*[25]

**32.** The Rare Auto Immune Rheumatic Disease (RAIRD) Alliance highlighted the importance of multi-disciplinary working to providing effective care to people with RAIRDs, because the nature of RAIRDs means that they often involve multiple organs throughout the body. However, it went on to say:

*"[…] our 2018 survey showed that there is a disparity in access to multidisciplinary care in Wales, compared to the rest of the UK.*

[22] RoP, 19 June 2024, para 14
[23] CC76 Public Health Wales
[24] CC55 Fair Treatment for the Women of Wales
[25] CC41 Dee Montague-Coast

> *9% of respondents living in Wales reported they had been able to access care at a joint clinic with doctors from multiple different specialties, compared to 17% across the rest of the UK."*[26]

**33.** Andy Bell, Chief Executive of the Centre for Mental Health, argued that wrap-around services should understand that "health is socially and economically constructed" and should therefore include additional types of support:

> *"So, it's things like being offered support with money, with housing, relationships, debt, work—all these things are incredibly important—support with education for children living with long-term physical or mental health difficulties. And person-centred care, really, is simply about realising that the individual is the expert in what they need and providing a range of support around people."*[27]

**34.** The Cabinet Secretary told us that, while she believed we have one of the most effective healthcare systems in the world, we have to adapt and address the issue of multimorbidity:

> *"One of the ways we're doing that is we've got 'A Healthier Wales', which, as you know, is our strategic programme for health in Wales. We're doing a refresh of that at the moment, to take into account what the future looks like, taking into account that 10-year vision for what health in the future looks like, and how we're going to adapt our systems to look at that. And those chronic conditions and multiple conditions that people are suffering at the same time are, obviously, something that are going to be central to that refresh."*[28]

## Giving patients a voice in their own care

**35.** A key part of delivering person-centred care is providing time for patients to have conversations about what matters most to them in their treatment.

**36.** Dr Rowena Christmas told us:

[26] CC25 Rare Auto Immune Rheumatic Disease Alliance
[27] RoP, 17 April 2024, para 15
[28] RoP, 19 June 2024, para 8

> *"... the doctor has got their expertise as from their medical degree and their further training, but you see the patient as the expert in their own condition. So, you're two experts trying to meet common ground. And that enables us to have a sort of more holistic approach; we can see the patient as a person within their environment, looking at their social factors and their environmental factors. And we know that if we can get this right, involve family and friends and carers, get the whole picture, that's going to decrease costs for the NHS, which is important, but equally, it's going to significantly increase patient satisfaction, and we're going to get a better outcome in the long run, so it's a good thing."*[29]

**37.** 'What matters' conversations were introduced by the Social Services and Wellbeing (Wales) Act 2014[30] as part of the social care assessment process. In March 2023, an evaluation of the Act[31], commissioned by the Welsh Government, found that 'what matters' conversations were broadly viewed positively by practitioners and seen as a return to good practice, and a way of changing the 'story' to focus on outcomes. The views of people accessing services was, however, more mixed, with some expressing disappointment following a 'what matters' conversation.[32]

**38.** The evaluation found that, in order to be effective, 'what matters' conversations take time and "need to involve the whole network of support around individuals." It also found that communication between health and social care could be challenging, with pressures in the system preventing meaningful conversations from taking place. Further, that it is important that 'what matters?' conversations are transparent regarding the services and support that are possible, in order to avoid raising expectations that may then not be met.[33]

**39.** Zoe Wallace, Public Health Wales, told us:

> *"It's very much ensuring that we're delivering evidence-based medicine to individuals to suit their health conditions and their lifestyles. So, it's those 'what matters to you' conversations, so*

[29] RoP, 8 February 2024, para 12
[30] Social Services and Well-being (Wales) Act 2014
[31] Final report: evaluation of the Social Services and Well-being (Wales) Act 2014, March 2023
[32] From Act to Impact? Final report of the evaluation of the Social Services and Well-being (Wales) Act 2014, March 2023
[33] Well-being: Research to support the Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014, March 2023

> *that we're tailoring interventions to maximise that individual's outcomes and potential to benefit."*[34]

**40.** However, Dai Davies, Royal College of Occupational Therapists (RCOT), told us that the interpretation of the 'what matters' conversation can be too narrow:

> *"Someone's quality of life is not just getting on and off the toilet and on and off the bed; it's to do with stuff like, if you love gardening, it's being able to go to the garden, and do your gardening, and [occupational therapists] try to do interventions that get people out and about, which they've been criticised for. But if you keep getting people out and about, that reduces muscle wastage, it improves mental health, so the policy, the legislation, says, the 'what matters' conversation—the reality is still quite rigid, and our members really, really fight against that."*[35]

### Individual care plans

**41.** In 2015, the Welsh Government made a commitment[36] that people living with chronic conditions could have an individual care plan if they wanted one. It published guidance[37] setting out the core characteristics of the plan:

- Holistic care and support – "Seeing the individual as a whole, taking into account all aspects of their life, not just treatment"
- Co-ordinated and integrated care and support – "Everyone involved working and communicating together"
- Individuals involved and engaged – "Professionals working in partnership with individuals"

**42.** Evidence from the Welsh Government states:

> *"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*

[34] RoP, 24 January 2024, para 97
[35] RoP, 8 February 2024, para 237
[36] My Health in My Hands, Public & Patient Guide to Individual Care Plans for People with Long Term Conditions
[37] Agreeing Individual Care with People who have Long Term Conditions

> *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."*[38]

**43.** Dr Frank Atherton, CMO, said he was sure that individual care plans are the "right direction to move in" and "to make sure that they work across the whole system." However, he said:

> *"Has it bedded in yet? There's more to do. Can we demonstrate the impact of that? Well, it's kind of anecdotal, I suppose. People do like to have an individual care plan. I think they benefit from that. It helps to co-ordinate the care around the patient (…) But I don't have any hard data to say that that's happened yet."*[39]

**44.** We asked the Association of Directors of Social Services (ADSS) whether there was enough awareness generally of individual care plans in all areas of health and social care. Jacquelyn Davies, Head of Adult Social Care at Bridgend County Borough Council), told us:

> *"… it's a requirement under the Act in social care for us to be equal partners in that {individual care plans]. I would say that there are pockets of really good practice where it is health and social care and the individual that are part of that, but it's not across the whole system, and that is something that we could work towards doing."*[40]

### Self-management

**45.** According to ADSS Cymru:

> *"For self-care needs to be addressed, opportunities for individuals to talk about their diet, routines and lifestyle management, need to be incorporated into the encounter. Care plans can help to facilitate this discussion. However, what is vitally important to support individuals with their self-care*

[38] HSC Committee, 19 June 2024, Paper 1
[39] RoP, 17 April 2024, para 153
[40] RoP, 14 March 2024, para 42

> *management is the recognition of the value of the person's knowledge and experiences."*[41]

**46.** The Older People's Commissioner for Wales also talked about older people being 'experts by experience' in terms of day-to-day management of chronic conditions and what works or does not. She said, 'this expertise needs to be recognised by health professionals in the management and recommendations surrounding ongoing treatment and support'.[42]

**47.** Written evidence from the Royal College of Psychiatrists Wales says there are 'many examples of support available to enable effective self-management where appropriate, including mental health support'. It highlights the example of the Technology Enabled Remote Monitoring in Schools (TERMS) project led by TEC Cymru, which focuses on young people with eating difficulties in schools:

> *"The project has a wider clinical utility, and the methodology can be further applied to medication management, and supporting people with ADHD for example; this may help tackle some of the existing challenges across services, such as around waiting lists and access to services."*[43]

**48.** Evidence from the Therapies Directorate at Cardiff & Vale University Health Board highlights the example of the Living Well Programme developed by Cardiff and Vale AHP services, which provides a range of self-management education and support, including programmes on exercise and increasing activity; food and nutrition and psycho-social and well-being support. However, it goes on to say that while there are pockets of good practice offering support to patients to self-manage their condition, access to these services needs to be widened.[44]

**49.** Arthritis and Musculoskeletal Alliance believed that health coaching should be part of any long-term plan to improve outcomes for patients with chronic conditions:

> *"Working in partnership, this involves health and care practitioners guiding patients to make decisions based on their individual circumstances and what is important to them, empowering them to become active participants in their health and care. Training in health coaching should be*

[41] CC78 Association of Directors of Social Services (ADSS) Cymru
[42] CC71 Older People's Commissioner for Wales
[43] CC46 Royal College of Psychiatrists Wales
[44] CC33 Therapies Directorate at Cardiff & Vale University Health Board

*provided for health and social care professionals to ensure this form of self-management is as effective as possible."*[45]

**50.** While Versus Arthritis suggested:

*"Consideration should be given to the potential value in developing a National Supported Self-Management Strategy for People with Long-term Conditions to share best practice across conditions areas."*[46]

**51.** Crohn's & Colitis UK says that to enable people living with Inflammatory Bowel Disease (IBD) to effectively self-manage their condition there needs to be a shared understanding of what self-management means, for current organisational culture and working practices to change by embedding a personalised, structured and consistent approach to care, that supports and empowers patients to self-manage their condition, while allowing ongoing clinical monitoring and direct access to specialist care:

*"While conditions such as cancer and asthma have seen investment and commitment to meet these needs, there has not been the same recognition, urgency, or proliferation of holistic or person-centred interventions in IBD. Structured self-management programmes, such as those available for other chronic conditions, should be provided on the same basis for people with IBD."*[47]

**52.** It suggests that consideration should be given to how best practice can effectively be resourced and rolled out across Wales and systems for meaningful patient involvement.

**53.** The Cabinet Secretary told us:

*"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*

[45] CC53 Arthritis and Musculoskeletal Alliance
[46] CC74 Versus Arthritis
[47] CC29 Crohn's & Colitis UK

*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."*[48]

**54.** We also heard about the importance of apps in helping people manage their conditions. Evidence from Asthma and Lung UK Cymru drew attention to three free-to-use self-management apps launched in 2020 to help people manage their asthma treatment and care. A survey conducted in 2022 to evaluate their success showed an improvement in condition management after using the app, with many people reporting a decrease in GP visits and accident and emergency admissions for their respiratory condition. It says:

*"The benefits of using digital health solutions in healthcare seem obvious; there can be more convenience and agency for users in monitoring their own health, healthcare costs to the NHS can be drastically cut down and there can be easier and more efficient patient data collection for healthcare professionals to make informed decisions about care. The challenge lies in encouraging people to download them and continuing to use them."*[49]

**55.** The Cabinet Secretary told us:

*"There are people who are brilliant at using their apps and their technologies to monitor their COPD conditions. They already exist. How do we increase that number, as we get increasing numbers, of people to help themselves? I think digital technology, for me, is going to be absolutely key to unlocking some of that."*[50]

## Unpaid carers

**56.** Some people living with chronic conditions rely on the support given by family or friends as unpaid carers. The needs of carers emerged as a theme of the

[48] HSC Committee, 19 June 2024, Paper 1
[49] CC08 Asthma & Lung UK Cymru
[50] RoP, 19 June 2024, para 48

Committee's stakeholder discussion. Participants emphasised that unpaid carers are not volunteers, but are acting out of necessity and love.

**57.** The Welsh Local Government Association highlighted 'increasing concerns for unpaid carers who carried out their critical role under severe pressure throughout the pandemic.' It said:

> *"While carer's services have continued to support people, there has been an increase in demand, with concerns that if unpaid carers are unable to continue to care effectively, then there will be increased demand for support placed on already overstretched services."*[51]

**58.** People who took part in interviews with our Citizen Engagement Team talked about 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."*[52]

**59.** Similarly, Dr Ian Davies-Abbot told us:

> *"Family carers describe having to 'fight' for the support they need and having to 'chase' clinicians for appointments. They often do not feel listened to and lack confidence in clinicians. They have also expressed concern that people who do not 'fight' will be missed and are distressed when they are excluded from the diagnostic process."*[53]

**60.** Jacqueline Davies, Association of Directors of Social Services Cymru (ADSS), said that "'what we need is for carers to have the right information, at the right time, by the right professional.'

> *"[…] right from the onset, when people have caring support needs or they have a diagnosis, they need the right information at the right time, and that might be available for some parts of the system, but might not be available for all, really. Carers organisations have got a wealth of information about how they*

[51] CC47 Welsh Local Government Association
[52] Supporting people with chronic conditions: Engagement findings, June 2024
[53] CC17 Dr Ian Davies-Abbot

> *would want the system to be improved, and we should draw on their expertise, really."*[54]

**61.** Both Jacqueline Davies and Fôn Roberts, also from the ADSS, warned that local authority cuts to support services are making it more challenging to support unpaid carers:

> *"As we move into the next financial year and the years that are coming, some of the facilities that you talked about, like luncheon clubs, support for the third sector, they are the things that local authorities are looking at and potentially putting up as savings, in order to meet their base budgets, really. So, I think it's going to get harder as we go forward, and it's going to get more difficult for us to do some of that lower level support for carers, as we go forward, really."*[55]

**62.** The Welsh Government published its Strategy for unpaid carers[56], which set out its revised national priorities for unpaid carers and priority areas for action in March 2021.

## Quality Statements

**63.** The Welsh Government has published Quality Statements for a number of chronic conditions, including diabetes[57], stroke[58] and respiratory disease[59]. There is also a Quality Statement for women and girls' health[60], which includes chronic conditions where "there is gender inequality and a need for gender competent services that women might require differently to men" like endometriosis. The Quality Statements underpin the National Clinical Framework[61], introduced by the Welsh Government in 2021, which sets out a vision for the strategic and local development of NHS clinical services, in response to population need.

**64.** Accountability for meeting the standards set out in the Quality Statements is provided by the NHS Executive. The National Clinical Framework says that the NHS Executive will "use data to benchmark services to support accountability

[54] RoP, 14 March 2024, para 118
[55] RoP, 14 March 2024, para 123
[56] Strategy for unpaid carers, March 2021
[57] Quality statement for Diabetes
[58] The quality statement for stroke
[59] Quality statement for respiratory disease
[60] Quality statement for women and girls' health
[61] National Clinical Framework: A Learning Health and Care System

discussions with the Welsh Government and support public transparency of service delivery."

**65.** While Quality Statements were generally seen as a positive step, we did hear some concerns regarding implementation and monitoring.

**66.** Calum Higgins, Chartered Society of Physiotherapists, described Quality Statements as a "step forward", but said that the Welsh Government needs to be making sure that they are enforced and being delivered at a local level. He said:

> *"I'm not sure who's checking and I'm not sure if there's real follow-up. It's assumed, I think, that everyone takes the standards and cracks on and does the work."*[62]

**67.** Referring to the Quality Statement for respiratory disease, Asthma and Lung UK Cymru stated:

> *"The quality statement contains positive aspirations, but without an implementation plan, it is difficult to see how change will be delivered within health boards. The Welsh Government announced a Cancer Services Improvement Plan in January 2023 but are not planning to develop improvement plans for other conditions. With 1 in 5 people affected by lung conditions and Wales having the highest level of respiratory deaths of any nation in Western Europe, we believe we need an improvement plan to implement the new quality statement."*[63]

**68.** The Cabinet Secretary told us:

> *"Certainly, one of the things that we have now is the quality statements, where we explain what 'good' looks like. That's very important. And then, the NHS executive's role is to ensure that that's carried out. [ ] There are examples of good practice and excellent work that make such a difference to patients and save money for the NHS, but there are pockets where this isn't being shared. So, what's important to me, then, is how we move from those good-practice pockets to a situation where it's happening across the board across Wales."*[64]

[62] RoP, 8 February 2024, para 206
[63] CC08 Asthma and Lung UK Cymru
[64] RoP, 19 June 2024, para 98

## Our view

**69.** This inquiry has highlighted the changing role of health care, as demographics and the nature of illness changes. The Welsh Government has, itself, identified an ongoing, relative shift away from acute illness towards longer-term, chronic conditions, with statistics showing that around 46 per cent of adults live with a long-term illness.

**70.** Looking ahead, that prevalence of chronic conditions amongst the general population looks likely to increase, along with the number of people likely to be living with two or more longstanding illnesses. Some estimates suggest that, by 2035, 17 per cent of the UK population will have four or more chronic conditions.

**71.** We know that those living with multiple chronic conditions often have greater health care needs. There is also growing evidence to show that living with multiple chronic conditions is associated with increased or premature mortality, lower quality of life, greater use of health services and a higher risk of disability.

**72.** Although some of the predicted rise in chronic conditions can be attributed to an aging population, people of any age can have such a condition. The number of people under 65 years of age with more than two conditions is higher than the number aged 65 and over.

**73.** This rising trend in the number of people living with one or more longstanding illnesses poses a significant threat to the future sustainability of the health and care system in Wales, putting enormous pressure on the Welsh NHS, social services and the third sector. As we heard, our health and care services tend to be focused around a single condition, rather than the multiple conditions often experienced by people living with long-term illness. These services are often not person-centred and can lead to multiple interactions with healthcare professionals.

**74.** Whilst the Welsh Government has identified the importance of a 'person-centred approach' in its long term plan for health and care services, it is very clear from the evidence we heard, both from healthcare professionals and people living with long-term conditions, that this is not being implemented consistently, and certainly not at the scale and pace that is needed.

**75.** In order to end this 'postcode lottery' for people living with chronic conditions, there must be a renewed focus on delivering services that are designed around the patient, and not their condition. These services should recognise that the individual is an expert in their own condition, and should

provide different types of care, support and treatment in a co-ordinated way that meets their needs, and supports them in managing their own health and care. It should also consider their carers and families.

**76.** The extent of the changes needed to achieve this should not be underestimated. Such a long-term transformation towards person-centred, closer-to-home services will require strong leadership and direction from the Welsh Government, and a commitment to monitor delivery rigorously. It will take time, and require greater alignment with related services and accompanying investment.

**77.** In the meantime, more needs to be done now to support people living with chronic conditions to ensure they are partners in their own care. They need long-term, person-centred support and care packages, rather than the current short-term interventions that they tell us are so frustrating and demoralising. People living with chronic conditions are experts in managing their conditions and that expertise should be recognised and respected. Individual care plans can help co-ordinate the care around the patient, as well as helping patients to manage their own conditions. While there are pockets of good practice in their provision, this is not consistent across Wales. We therefore believe that the implementation of individual care plans should be urgently reviewed to ensure that everyone who is eligible to receive a plan is offered one as a matter of course. We also know that the opportunity to talk to a healthcare professional, ideally during a face-to-face appointment, about their treatment options and what matters to them is incredibly important to people living with chronic conditions. Therefore time needs to be made available for these discussions to take place.

**78.** Self-management of chronic conditions is important, and patients should be supported to self-manage, where that is appropriate for them. Increasing knowledge and understanding of their conditions can give people the skills and confidence they need to manage their own health and care. Signposting to, and raising awareness about, charities and support groups is important in this respect. There are also a number of digital applications available to help with self-management. However, apps are not suitable for everyone so these should not be a substitute for community based support and advice.

**79.** Unpaid carers play a huge role in supporting people with chronic conditions. They are not volunteers, but act out of love and necessity. It is vital that they receive the recognition and support they deserve. We therefore welcome the Welsh Government's commitment in its refreshed actions to support the delivery

of A Healthier Wales[65] to ensure individuals and their carers are enabled to work as key partners in co-producing and owning their own health and care plans.

**80.** We know that services providing much needed respite for carers, such as day centres, were badly affected during the pandemic. While some of these services have resumed, it is concerning to hear that they are the most likely to be impacted by local authority spending reductions. We will consider this as part of our forthcoming work on the Welsh Government's draft budget 2025-26.

**81.** Quality statements set the standards and quality of care that individuals can expect when accessing health services. While their introduction seems to have been a positive step in principle, we share the concerns of witnesses about how they are being implemented in practice, and how their delivery is monitored. It is also disappointing to hear from the Cabinet Secretary that examples of good practice in this area are not being widely shared across Wales. We believe there is a need for increased clarity and transparency as to how health services are being held to account for meeting these standards.

**Recommendation 1.** The Welsh Government must take urgent action to ensure a renewed focus on the delivery of person-centred health and care services that are designed around the individual, not their condition. In its response to this report, the Welsh Government should set out the work it is doing to implement its refreshed actions to support its 'A Healthier Wales' strategy. This should include specific milestones for delivery of the refreshed actions, and an assessment of how they will improve care and services for those living with chronic conditions.

**Recommendation 2.** The Welsh Government should work with health boards to explore reorientating services to 'wrap around' patients living with chronic conditions, providing 'one stop shop' clinics that combine different services and medical professionals in one place. In its response to this report, the Welsh Government should provide details of current work to provide services in this model, and then provide an annual update to us with examples of new services that are being developed.

**Recommendation 3.** The Welsh Government should review, as a matter of urgency, the use of individual care plans for patients with chronic conditions to ensure that all eligible individuals are offered a plan as a matter of course, and to ensure consistency of practice. It should report back to this Committee with the findings of this review 12 months after the publication of this report.

[65] A Healthier Wales: our Plan for Health and Social Care – Action Refresh, December 2024

**Recommendation 4.** The Welsh Government should set out how it intends to ensure the NHS Executive will monitor and enforce the consistent delivery, by health boards, of the standards for care set out in Quality Statements, and how this will improve the quality of care provided.

# 3. Interaction with healthcare professionals

## Capacity in primary care

**82.** Dr Frank Atherton, Chief Medical Officer for Wales (CMO), said:

> "Primary care, as I'm sure we all would recognise, is very significantly overloaded, and we need to think about how primary care can best meet the needs of people with multiple chronic conditions. Primary care is the place where most health services should be provided, but it's under significant stress."[66]

**83.** According to the Royal College of GPs (RCGP), "patients with long-term conditions account for around 50% of all GP appointments."

**84.** In a UK wide press release issued in 2019, former UK Chair Helen Stokes-Lampard:

> *"It is abundantly clear that the standard 10-minute appointment is unfit for purpose. It's increasingly rare for a patient to present with just a single health condition and we cannot deal with this adequately in 10 minutes."*[67]

**85.** Four years on, RCGP Wales members are expressing the same concerns:

> *"Members are worried about not being able to provide adequate care in the short time they get to see a patient. It is challenging in the current climate to build relationships with patients that would lead to building a full picture of their health needs."*[68]

**86.** Participants in our stakeholder event told us that health professionals often don't have a lot of time to spend with patients, and suggested one way to overcome this would be better signposting to help people self-manage their conditions."[69]

[66] RoP, 14 April 2024, para 142
[67] CC69 Royal College of General Practitioners
[68] CC69 Royal College of General Practitioners
[69] Supporting people with chronic conditions: stakeholder discussion 28 February 2024

**87.** Dr Rowena Christmas told us:

> *"I think we need to give ourselves more time with patients. We've gone up to 15 minutes in my practice with each patient, and even that's quite tight. So, with endless amounts of money and endless amounts of doctors it would be easy; we would have half an hour with each patient. But that's not realistic. So, I think what we need to do is have the GPs with more time with the highly complex patients, and then develop our primary care multidisciplinary teams, with our excellent nurse practitioners, paramedics and practice-based pharmacists seeing other patients."*[70]

## Understanding the patient experience

**88.** People who took part in interviews with our Citizen Engagement Team talked about not being listened to or being dismissed by healthcare professionals. One told us:

> *"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."*[71]

**89.** While another said:

> *"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."*[72]

**90.** Some participants gave examples of excellent, "second to none" medical and healthcare services, on all levels. However, others spoke about the need for empathy and a better understanding when addressing people with chronic conditions, and called for updated training and refresher courses.

**91.** Participants in our stakeholder event told us that people living with multiple chronic conditions can experience 'diagnostic overshadowing', where one condition is blamed for all symptoms and other causes are not adequately explored. They said that this is true of physical and mental health, where symptoms with physical causes are blamed on mental health conditions like

[70] RoP, 8 February 2024, para 41
[71] Engagement findings, June 2024
[72] Engagement findings, June 2024

anxiety and depression, and similarly mental health symptoms are blamed on physical conditions. They believed that training for medical professionals was important to address this.

**92.** According to the Women's Health Wales Coalition:

> *"The ability of the NHS to respond to the needs of patients with chronic conditions also very much depends on the quality and effectiveness of training undertaken by Wales's health and care professionals."*[73]

**93.** Participants in our roundtable stakeholder event told us:

> *"More recognition is needed that engaging with medical professionals can be challenging and even traumatising in some circumstances. Training, both during initial medical training and as part of CPD, should be provided to help medical professionals understand patients' experiences of accessing healthcare, unconscious bias, and understanding of intersectional barriers in healthcare."*[74]

## Continuity of care

**94.** Dr Christmas talked about the strength of the relationships GPs can develop over time with their patients:

> *"Patients with longer term relationships with their doctors are more likely to follow advice. They're more likely to challenge their doctor if they disagree. They're more likely to take their medication. That overarching leads to much less likely to need emergency services, much less likely to be referred to hospital or be admitted. So, again, it decreases costs, keeps care closer to home, gives the patient the outcome that works for them and their family. So, relationship-based care is absolutely key to managing chronic conditions well."*[75]

[73] CC30 Women's Health Wales Coalition
[74] Supporting people with chronic conditions: stakeholder discussion, 28 February 2024
[75] RoP, 8 February 2024, para 20

**95.** She warned that a focus on access in primary care might mean not enough focus on the quality of care provided, or on the importance of continuity of care, particularly for those with chronic conditions:

> *"So, we've got to push away from access being the absolute holy grail; it isn't. Continuity and understanding the patient in their lives, in their conditions, that's the holy grail"*[76]

**96.** The Older People's Commissioner for Wales also highlighted the importance of continuity of care and being able to access the same GP. She said that developing relationships with individual GPs can be helpful in managing ongoing conditions:

> *"This can be especially important where older people's first language is Welsh or a community language - being able to speak to a GP in an individual's first language makes it easier to explain symptoms and developments."*[77]

## Use of multi-disciplinary teams

**97.** We heard about the important role of the multi-disciplinary team in supporting people with chronic conditions.

**98.** Evidence from the Royal College of Physicians of Edinburgh stated:

> *"We consider that a multidisciplinary team approach can be of real benefit to patients in this context, including the involvement of allied health professionals. Again, it is critically important for there to be sufficient numbers of health and social care staff, including general practitioners, general physicians and psychiatrists, to allow multidisciplinary teams to function effectively."*[78]

**99.** Zoe Wallace, PHW, told us "the contribution the allied health professionals bring to health and well-being is significant". She went on to say,

> *"... we've got an increasing number of healthcare professionals now being based in general practice, so you may well see a physiotherapist or a pharmacist, or another physician other*

[76] RoP, 8 February 2024, para 24
[77] CC71 Older People's Commissioner for Wales
[78] CC09 Royal College of Physicians of Edinburgh

> *than a nurse or a GP in terms of your chronic condition management, depending on your presenting needs."*[79]

**100.** An Allied Health Professions Framework for Wales[80] was published in 2018. Dai Davies, RCOT, said that Wales is a "forerunner in Britain" in the multi-disciplinary model for primary care and that delivery in GP surgeries is "a bit of an envy of the rest of the UK."

**101.** Dr Rowena Christmas, RCGP, said that while multidisciplinary teams in primary care can free up GPs' time, giving them more opportunity to work with highly complex patients, managing and supervising multidisciplinary teams can itself take time. She said:

> *"Everybody needs to be working at the top of their ability, but with enough time to do that work and enough time to supervise the multidisciplinary team as well. But we will definitely provide a more quality service if we've got the time to do it."*[81]

**102.** Calum Higgins, Chartered Society of Physiotherapists, told us how AHPs specialise in a holistic, round look at someone's health:

> *"Sometimes, we over-medicalise, probably, in the NHS, and in providing services, we look at the medical viewpoint, whereas AHPs bring a multidisciplinary look at someone's life, how they can carry on living as healthily as possible with whatever condition they have, or multiple conditions, as we're seeing increasingly. They look at the person and what they can achieve and what they want from their health and their lifestyle, rather than maybe just simply treating something that's been diagnosed."*[82]

**103.** Both Calum Higgins and Dai Davies, Royal College of Occupational Therapists, highlighted the importance of AHPs seeing patients early in their treatment. Calum Higgins told us:

> *"[…] maybe we need to look at putting it at the beginning of a patient's journey, having prehab before someone goes in for*

[79] RoP, 24 January 2024, para 206
[80] Allied Health Professions Framework for Wales - Looking Forward Together
[81] RoP, 8 February 2024, para 41
[82] RoP, 8 February 2024, para 131

*treatment, speaking to OTs, physios, speech and language therapists earlier on in the journey so that we, maybe, avoid some of those hospital admissions that we see, and allow people to live longer, healthier lives."*[83]

**104.** The British Psychological Society highlighted Powys Teaching Health Board's Living Well Services as an example of successful, multi-disciplinary working in primary care for people with chronic pain:

*"The service is led by a psychologist working with a multidisciplinary team of physiotherapists, nurses and GPs. They work with people who have persistent pain, chronic fatigue or significant weight issues to understand how their health problems effect the physical, psychological and social aspects of their lives and understand what they can do to manage their conditions and live well."*[84]

**105.** The Cabinet Secretary also referenced the role of the multi-disciplinary team, saying:

*"[…] one of the challenges we have is that we can't rely entirely on GPs. Actually, we've got a much broader model than that now, where we are making sure that there is much broader support, so that people can go and perhaps see an allied health professional that may be able to help them with one of their chronic conditions. It doesn't have to be the GP. And there is a bit of work to do, I think, with the public, to make sure that they understand that the GP doesn't have to always be the first port of call."*[85]

**106.** She went on to highlight the additional funding made available for recruitment of Allied Health Professionals:

*"Just on the AHPs, we have invested an additional £5 million to ensure that more AHPs are recruited, and that is making a huge difference. I met a number of occupational therapists yesterday who told me how much of a difference that investment has already made. So, this is also part of the clear*

[83] RoP, 8 February 2024, para 132
[84] CC54 British Psychological Society
[85] RoP, 19 June 2024, para 15

> *strategy that we have in terms of moving investment into our communities away from hospitals."*[86]

**107.** The Royal College of Podiatry told us that while the Welsh Government has been clear that it wants more people to have more opportunity for direct access to a wider range of allied health professionals in the community:

> *"None of this will be possible without sufficient podiatrists, and other AHPs, being trained. We are concerned that future service needs have not been reflected in commissioning numbers to date and that there is no workforce plan for AHPs."*[87]

## Communication between primary and secondary care

**108.** People living with chronic conditions, and particularly those with multiple chronic conditions, can need complex care that involves multiple professionals. .

**109.** Dr Hilary Williams, Royal College of Physicians (RCP), believes that primary and secondary care are too distant from each other. She said:

> *"[…] if you think of the patient at the heart of that, they are going often between different systems, particularly with cancer or a complication that does require hospital care. […] people are sort of falling between the gaps, and something so basic as a discharge summary, or what I'd call a discharge summary, which is a letter written by, often, the doctors when someone leaves hospital, it bears no relation to what a clinician in the community might need."*[88]

**110.** This was echoed by Lisa Turnbull, RCN, who described an "almost breakdown in communication" between primary care and hospitals. She went on to say:

> *"But there's also an equally significant breakdown of communication with the community nursing team, who are often, post operation, post hospital, providing that care. That lack of information on patients discharged into the responsibility of that team, and people in that team scrambling then to try and put stuff together, is extremely important."*[89]

[86] RoP, 19 June 2024, para 39
[87] CC21 Royal College of Podiatry
[88] RoP, 8 February 2024, para 22
[89] RoP, 8 February 2024, para 49

**111.** Dr Frank Atherton, CMO for Wales, told us that that a protocol[90] had been developed about three or four years ago because it was recognised that there was a problem on the interface between primary and secondary care:

> *"It was a protocol for working between those two parts of the system. I think that was quite useful. It's been very useful. But it's now a bit out of date. I've just been asking my colleagues who work in the Welsh Government […] to have another look at that and see if we can improve the way that that helps to smooth that interface between primary and secondary care."*[91]

**112.** Dr Stuart Hackwell, Senior Medical Officer for Primary Care and Mental Health in the Welsh Government, confirmed that the all-Wales communication protocol referred to by Dr Atherton had been revised and was currently being consulted on.

## Learning from disciplines that treat multiple conditions

**113.** In 2020, the Chief Medical Officers (CMOs) of the four nations of the UK wrote that managing multiple chronic conditions poses a significant challenge to health and care services, which have often developed to treat single conditions in isolation. They wrote that "training and service organisation are not optimised to face a multimorbidity dominated future."[92]

**114.** The CMOs also wrote that some specialties already have 'multimorbidity at their heart'. They highlighted diabetologists who 'already provide care for the cluster of multiorgan diseases around diabetes'. Similarly, the National Institute for Health and Care Research (NIHR) suggested the care of older people and children with complex needs as examples of clinical areas where it is the norm to care for people with multiple chronic conditions.[93]

**115.** We therefore invited representatives from Diabetes UK Cymru, British Geriatrics Society Wales (BGS) and the Royal College of Paediatrics and Child Health (RCPCH) to give evidence to Committee to share their experience of health care disciplines that have the treatment of multiple chronic conditions at their heart. We also sought written evidence from the Terrence Higgins Trust Cymru.

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[90] All Wales Communication Standards between General Medical Practitioners and Secondary care
[91] RoP, 17 April 2024, para 161
[92] BMJ, Rising to the challenge of multimorbidity, January 2020
[93] National Institute for Health and Care Research, Multiple long-term conditions (multimorbidity): making sense of the evidence, March 2021

**116.** Dr Nicky Leopold, BGS, talked about redeveloping services to offer "hospital at home, virtual ward-type settings", so that care that is equivalently safe to hospital services is available in patient's own homes. She described a service in Neath and Swansea:

> *"... with a very, very good, responsive acute clinical team, to the extent that, often, patients living in that area with chronic conditions will not really think of hospital as necessarily being the go-to place for them, accepting that, if they're able to get very similar care in their own home that is timely and reactive, they will often do better."*[94]

**117.** The Terrence Higgins Trust welcomed the "ambitious" HIV Action Plan and the positive work that has begun to happen to implement it, including a new patient management system "which will allow a national picture to be created of those lost to care and living with the virus." They shared examples of projects in England that could be encouraged in Wales, where support workers were embedded in HIV clinics to provide tailored support and reduce missed appointments.[95]

## Learning from good practice

**118.** Throughout this inquiry, we have been told about pockets of excellent care throughout Wales. However, witnesses also said that these examples can be fragmented and that there are limited opportunities to learn from and disseminate good practice.

**119.** Zoe Wallace, Public Health Wales, said:

> *"And that's one thing that we're not that good at doing in Wales. We have pockets of excellent service across our NHS community, but we're not that good at scaling and spreading, and that's something that we need to get better at in terms of systematising our health and care pathways. We do need to recognise that what works in one area may not easily be transposable to another because of rurality, geography, et cetera, but the principles of ways of working we can scale and spread and adopt."*[96]

[94] RoP, 14 March 2024, para 157
[95] Letter from Terrence Higgins Trust Cymru, 28 March 2024
[96] RoP, 24 January 2024, para 120

**120.** Dr Hilary Williams ,Royal College of Physicians (RCP) highlighted some examples in acute oncology, which involved bringing solutions from the shop floor rather than imposing them from above. However, she went on to say:

> *"... I think we have to be realistic that, in Wales, we are a smaller country and we are trying to do an awful lot, and I think we have to perhaps be a bit bolder and say, 'These are the things that are really going to make a difference in the next three years. Let's really empower our staff and deliver on those', rather than doing too many things [ ]. What I see a lot of is very good policy that doesn't get delivered, [ ], and I think we have to stop writing documents and actually deliver what we know are some of the solutions."*[97]

**121.** Dr Nicky Leopold, BGS, said that while members of the British Geriatrics Society meet and share examples of good practice, there is currently no formal, Government-run way to share case studies. She said:

> *"But I do think that Government could play a role in showcasing good practice and actually encouraging: 'Oh, they did that really well here. What can we do to support this area in doing a similar thing?'"*[98]

**122.** Dai Davies, Royal College of Occupational Therapists (RCOT), suggested that there could be a central hub website to collect evidence about projects that have been successful. He said that this would avoid duplication and:

> *"... you'd be building services on key things that have been learnt. It's part of evidence-based practice; you don't do anything that harms people, so if you know that that service doesn't harm anyone because it's there, it saves lots of time and money and it's an efficient use of resources."*[99]

**123.** The Cabinet Secretary agreed that 'there are examples of good practice and excellent work that make such a difference to patients and saves money for the NHS, but there are pockets where this isn't being shared'. She went on to say:

> *"... what's important to me [ ] is how we move from those good-practice pockets to a situation where it's happening across the*

[97] RoP, 8 February 2024, para 32
[98] RoP, 14 March 2024, para 198
[99] RoP, 8 February 2024, para 278

> *board across Wales. One of the things I'm keen to look at is more of a system of adopt or justify, in that you have to do it or justify why you're not doing it. We're not in that place yet, but I hope that that's where the NHS executive and the clinical networks that we have will work and make it happen."*[100]

**124.** Calum Higgins, Chartered Society of Physiotherapy (CSP), referred to what he called "pilotitis", where:

> *"pilots are run, funding is a little bit inconsistent, and when that funding runs out, people take the learning but it doesn't really go anywhere nationally, in my opinion, and it doesn't get, then, from the top down, spread out across all health boards."*[101]

**125.** He said that this is particular problem for rehabilitation services, which have to be "packaged as something innovative and new and transformational" to secure temporary funding, which then runs out. He argued that these services should be "core funded" to provide stability.[102]

**126.** Similarly, Lisa Turnbull, RCN Wales, said that funding for community nursing is often funnelled through Regional Partnership Boards, so "the core community nursing service is engaged in rebadging itself, or rejigging itself in order to access these new pools of funding." She argued that the core funding of the community nursing team should be increased.[103]

**127.** The Cabinet Secretary told us that pilot programmes often fail or don't get the results expected:

> *"So, it's really interesting, for example, if you look inside the regional partnership boards, the idea behind them was that we would begin to see innovation, and that people would collaborate between the health boards and local government, for example. [ ] what's happened is that each one of them says, 'Our project is fantastic; look at ours', but what they don't do then is compare with different projects that are perhaps doing*

[100] RoP, 19 June 2024, para 98
[101] RoP, 8 February 2024, para 136
[102] RoP, 8 February 2024, para 152
[103] RoP, 8 February 2024, para 107

*better, but because they're so wedded to their own project, they don't want to let that go."*[104]

**128.** She went on to say that she believed there was a role for Government to look at which pilots were working best for patients, and also from a financial point of view.

**129.** In relation to funding for mainstreaming pilots, the Cabinet Secretary said:

*"... that additional funding isn't available, so it's up to the health boards to see whether this works and, if it works, they have to make space for that to work and stop doing something else. And that's what a number of health boards find difficult."*[105]

## Digital communication

**130.** A number of witnesses highlighted the importance of improving digital systems to enable better communication between different health and social care services. Dr Hilary Williams, RCP, told us, ' I think our digital services are letting us down.'[106]

**131.** When asked if he thought the systems currently in place to enable communication between different parts of the healthcare system were adequate, Dr Frank Atherton, CMO for Wales, told us:

*"It's not as good as it needs to be. We are one of the few countries in Europe that doesn't yet have a proper electronic healthcare record. I know this is a priority for the Minister, and that would go a long way to improving the communication between health professionals. I think things have got better than they used to be. In some cases, it's easier for general practice to talk to secondary care through Consultant Connect, for example. Those sorts of things do help, but they're not yet systematically embedded, I don't think, in our system sufficiently."*[107]

[104] RoP, 19 June 2024, para 102
[105] RoP, 19 June 2024, para 103
[106] RoP, 8 February 2024, para 22
[107] RoP, 17 April 2024, para 159

**132.** Evidence from MacMillan Cancer Support states:

> *"... to facilitate the effective delivery of care for people living with cancer there must be better record sharing across health and care systems. This is particularly true of people living with more than one chronic condition, where timely access to patient records for healthcare and other professionals is key to ensuring better outcomes and patient experiences and providing continuity of care across settings. There must also be interoperability between systems, to ensure records can be shared effectively."*[108]

**133.** The Cabinet Secretary admitted 'we haven't got a good track record not just in Wales, but across the UK in terms of digital roll-out.' She went on to say:

> *"We're getting there; it takes a long time. I think there are lots of lessons we can learn. One of the things that I'm very clear with my officials about now is that, where possible, we should be buying things off the shelf—tried-and-tested systems. You couldn't do that when we started introducing some of these things 10 years ago; those programmes didn't exist, so we had to build our own. That's no longer the case, so it's an area that is absolutely key. If you look at 'A Healthier Wales', digital transformation is absolutely front and centre, and it is really important to me."*[109]

## Our view

**134.** We recognise the importance of primary care for people living with chronic conditions and the impact a positive relationship between a patient and their GP can have. Having a good relationship with their GP is an important part of helping people manage their conditions - someone who knows their background and family circumstances, as well as their medical history.

**135.** We heard from GPs that they are concerned about their ability to provide adequate care in the short time they get to see a patient. We also heard from people living with chronic conditions that they often feel as though health professionals do not have a lot of time to spend with them.

[108] CC16 MacMillan Cancer Support
[109] RoP, 19 June 2024, para 85

**136.** Having one or more chronic conditions can be life changing and will inevitably lead to increased contact with medical professionals. Engaging with medical professionals can be challenging and even traumatising for some people, therefore it is important that patients feel their concerns are being taken seriously. We agree with witnesses that training, both during initial medical training and as part of CPD, should be provided to help medical professionals understand patients' experiences of accessing healthcare.

**137.** The multi-disciplinary team plays an important role in helping people to manage their own conditions, through provision of physiotherapy, speech and language therapy, pain management, etc. Seeing an Allied Health Professional early could help to avoid hospital admissions and improve quality of life. Increasingly, more of these services are being delivered in a general practice setting, so ensuring a sufficient Allied Health Professionals workforce is critical.

**138.** Related to this, we know there are people who would prefer to see their GP, even when an appointment with an Allied Health Professional would be more appropriate for their needs. Improving understanding of the role of the different members of the multi-disciplinary team could help to encourage behavioural change in this area.

**139.** People living with chronic conditions, and particularly those with multiple chronic conditions, can need complex care that involves contact with multiple professionals. Greater collaboration and communication is needed between different parts of the healthcare system to manage the care of those with chronic conditions to help avoid delays, duplication and confusion. We were particularly concerned to hear about the lack of communication around hospital discharge, given the danger of readmission as a result of poorly managed discharge.

**140.** As regards sharing good practice for supporting those living with chronic conditions, whilst there are pockets of excellent care throughout Wales, these are fragmented and there are limited opportunities to learn from and disseminate good practice. We agree with witnesses that there needs to be centralised way to share best practice case studies, and that the Welsh Government should take the lead in this work.

**141.** Pilot projects provide an opportunity to develop innovative ways of working. However, when project funding runs out, these services, and all that is learned, can be lost. Frustration about short term funding has been a theme in Committee inquiries over a number of years. However, we also believe that clarity is needed on how successful pilot projects are evaluated and mainstreamed.

**142.** Digital communication is a long standing and recurring theme throughout our work. Our report on the impact of the waiting times backlog on people in Wales, published in 2021, found that progress needs to be made on digital records and information sharing so that patients can receive seamless services from all parts of the health and social care system. Yet we are still hearing of outdated technology and systems that are unable to talk to each other. We appreciate that digital transformation takes time and is costly but we are concerned that Wales is behind the curve when it comes to digital communication.

**Recommendation 5.** The Welsh Government should work with the relevant professional bodies and Health Education and Improvement Wales to ensure that continuing medical education opportunities include the perspectives and experiences of patients living with chronic conditions, and promote empathic care.

**Recommendation 6.** The Welsh Government should work with NHS Wales to improve public understanding of the different roles of members of the multi-disciplinary team in primary care ensure that direct referral services provided by allied health professionals are clearly signposted to encourage their greater use.

**Recommendation 7.** In its response to this report, the Welsh Government should provide an update on the review of the All-Wales communication protocol between primary and secondary care, and set out how it is going to work with NHS Wales to improve communication between primary and secondary care.

**Recommendation 8.** In its response to this report, the Welsh Government should set out its approach to ensuring that good practice for supporting those living with chronic conditions is shared across health services in Wales, so that pockets of good practice become disseminated across the system. The Welsh Government should clarify the role the NHS Executive and clinical networks play in this work.

**Recommendation 9.** It is important that successful pilot projects which deliver improvements for patients are identified, so that good practice and innovation can be shared across Wales. Within 6 months of the publication of this report, the Welsh Government should set out clearly its own expectations of how the success of individual pilot projects should be evaluated by Regional Partnership Boards to encourage improved collaboration between services. .

**Recommendation 10.** The Welsh Government, in its response to this report, should provide an update on the development of the secondary care electronic health record by Digital Health and Care Wales.

# 4. Workforce

## Workforce pressures

**143.** We heard that workforce pressures are affecting many areas of health and social care, including staff in specialist mental health services, domiciliary care workers, and social workers.

**144.** Professor Jim McManus, PHW, said that the workforce is "tired and exhausted" after Covid-19, and warned that we "underestimate the burden that COVID is still creating for our staff and for our patients and for our workforce as a whole."[110]

**145.** The Royal College of Podiatry agreed, saying:

> *"Currently feedback that we receive from our members has highlighted significant issues of stress and burnout among the workforce, that have only been exacerbated by the pandemic, ultimately causing some to leave the NHS."*[111]

**146.** Evidence from the Royal College of Physicians of Edinburgh states:

> *"addressing the significant workforce challenges within the physicianly sector and all across health and social care is vital if our health and social care services are able to support effectively those living with long term conditions and multimorbidity and indeed all others using these services."*[112]

**147.** According to the Association of Directors of Social Services (ADSS) Cymru, workforce pressures are "hampering the system's ability to deliver high-quality, integrated, person-centred support to individuals with a chronic condition."[113]

**148.** In the Welsh Government's National Workforce Implementation Plan: *Addressing NHS Wales Workforce Challenges*, published in January 2023, the Cabinet Secretary says:

> *"These workforce issues are threaded through every discussion I have with NHS Wales staff and leaders and have been front*

[110] RoP, 24 January 2024, para 208
[111] CC21 Royal College of Podiatry
[112] CC09 Royal College of Physicians of Edinburgh
[113] CC78 ADSS Cymru

> *and centre in recent months. The message is clear – we must accelerate our action underpinned by strong, collective and compassionate leadership if we are to improve retention and recruitment and provide our workforce with the working environment and conditions that they need to be able to care effectively for the people of Wales."*[114]

## Specialist nurses

**149.** Specialist nurses play a key role in co-ordinating care for particular conditions or areas of practice and provide continuity for patients. Lisa Turnbull, Royal College of Nursing (RCN), highlighted the support that specialist nurses provide, such as:

> *"advice on management, practical, emotional advice on how to change one's life, adapt one's life, and flourish in one's life while having this chronic condition in the situation you describe."*[115]

**150.** Dr Rowena Christmas, RCGP, talked about the excellent Parkinson's specialist nurses who visit people at home:

> *"They're that point of contact (…) so the patients feel very safe with their Parkinson's specialist nurse that they can phone up and talk to."*[116]

**151.** She highlighted, however, that those living in deprived areas are less likely to have access to a specialist nurse. She said that with greater investment in "more specialist nurses in the communities where people are less well, we are much more likely to empower them to stay well and stay at home."[117]

**152.** Many of the people who took part in our engagement work also spoke about the benefits of having specialist nurses but noted the pressures on the specialist nurses themselves, as there are so few of them.[118]

**153.** A number of other witnesses highlighted difficulties in accessing the services of specialist nurses. The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) said:

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[114] National Workforce Implementation Plan: Addressing NHS Wales Workforce Challenges, January 2023
[115] RoP, 8 February 2024, para 75
[116] RoP, 8 February 2024, para 73
[117] RoP, 8 February 2024, para 86
[118] Engagement findings, June 2024

> *"In Wales, fewer respondents to our 2018 survey had access to a specialist nurse than anywhere else in the UK, and of those who did, Welsh patients reported the most difficulty in contacting their specialist nurse."*[119]

**154.** MS Society Cymru reported difficulties in accessing MS specialist nurses[120], and the All Wales Diabetes Patient Reference Group (AWDPRG) said that levels of Diabetes Specialist Nurse (DSN) availability are only just returning to normal after resources were re-directed to other streams during the height of the pandemic.[121]

**155.** Lisa Turnbull, RCN, argued that a lack of data and the lack of a postgraduate, post-registration commissioning strategy for nursing means that there a "quite random" approach to commissioning specialist nurse services. She told us that there is no centrally held data on the number of specialist nurses in Wales which, she said:

> *"... illustrates profoundly the problem that we have with specialist nurses. Because, where they exist, they are excellent. Now, if that nurse gets another job, or retires, who replaces that person? And then the entire service actually can collapse."*[122]

**156.** She went on to state:

> *"The Welsh government, through Health Education and Improvement Wales (HEIW), is responsible for commissioning the post-registration nursing education that can prevent this happening. This is why RCN Wales is concerned that the number of specialist nurses in Wales is unknown at the national level. The current unplanned approach means that geographical areas with the greatest need may not have a specialist nurse."*[123]

**157.** She told us that RCN Wales has been calling for a national postgraduate, post-registration commissioning strategy for nursing.

[119] CC25 Rare Autoimmune Rheumatic Disease Alliance (RAIRDA)
[120] CC51 MS Society Cymru
[121] CC73 All Wales Diabetes Patient Reference Group (AWDPRG)
[122] RoP, 8 February 2024, para 74
[123] Additional information from the Royal College of Nursing Wales, 29 April 2024

## Workforce planning

**158.** The Welsh Government's National Workforce Implementation Plan: *Addressing NHS Wales Workforce Challenges* states:

> *"We must develop whole workforce planning approaches to meet the needs of an older population, which ensures that the needs of this part of our population are embedded across professional education and supported through new models of multi-professional working and also addressed in our longer term strategic direction for health and social care."*[124]

**159.** The Royal College of Physicians of Edinburgh said:

> *"We believe comprehensive and detailed NHS and social care workforce planning is required to equip our services and allow them to meet the demographic challenges which will impact on all communities in the years ahead."*[125]

**160.** A number of witnesses highlighted the need for workforce planning to be based on projected population needs to ensure the sustainability of services.

**161.** Dr Hilary Williams, Royal College of Physicians (RCP), said that Wales needs better workforce planning to meet the needs of future populations. She said:

> *"I think we're all beginning to understand that the rural communities, which are a big issue for Wales, and the older population is growing and growing. I think [ ] we need to start planning our workforce based on that future need, not on this ad hoc basis. I think we need to be much braver about that, and probably not overcomplicate it, but we need the staff working in rural communities to do exactly all the things that we're talking about.."*[126]

**162.** Similarly, Lisa Turnbull, RCN Wales, said:

> *"... we actually need to look at the population and say, 'This is how many we need, let's do some succession planning for providing the education, so that, in five years' time, we will have*

[124] National Workforce Implementation Plan: Addressing NHS Wales Workforce Challenges, January 2023
[125] CC09 Royal College of Physicians of Edinburgh
[126] RoP, 8 February 2024, para 81

> *those people and we can provide those excellent services to the people who need them.'"*[127]

**163.** Dai Davies of the Royal College of Occupation Therapists told us:

> *"The visibility of the population needs assessment, in relation to workforce, isn't there. Our managers will do a population needs and workforce plan and that seems to get lost in the ether. There needs to be more clarity on how we workforce plan in relation to population health needs, rather than how we plan in relation to finance and process."*[128]

**164.** The Royal College of Podiatry highlighted that the Welsh Government's Workforce Implementation Plan recognised that training places for some professions have not been increased at the same rate as others, and that this needs to be considered moving into the future. It also raised concerns that future service needs have not been reflected in commissioning numbers to date and that there is no workforce plan for AHPs.[129]

**165.** In letter to Committee, HEIW said:

> *"We agree that there needs to be a focus on better workforce planning and we provide a range of resources and support to NHS organisations to ensure that collectively we are planning a future workforce that will be able to meet the needs of our population. These include better access to data and analytics, scenario planning and workforce planning guidance for areas like primary care."*[130]

## Our view

**166.** There are significant and well-documented challenges facing the health and social care workforce, exacerbated by the lasting effects of the pandemic. Witnesses have highlighted significant issues of stress and burnout among staff, with morale at an all-time low.

**167.** Addressing these issues of recruitment and retention within the health and social care sectors is fundamental to providing effective support to those living

[127] RoP, 8 February 2024, para 75
[128] RoP, 8 February 2024, para 153
[129] CC21 Royal College of Podiatry
[130] Correspondence from HEIW, 13 September 2024

with chronic conditions. We welcome the Welsh Government's continued investment in education and training of healthcare professionals and commitment to ensure the NHS has the workforce it needs to respond to the challenges it faces in the future.

**168.** More specifically, and for those living with long-term illnesses, the benefits of having access to a specialist nurse are clear, both in terms of helping to co-ordinate care and providing continuity for patients. It is also clear that there is a lack of specialist nurses in Wales, particularly in more deprived areas. Further, we were told that there is no centrally held data on the number of specialist nurses in Wales. We are concerned that without this data it is difficult to determine what the current workforce is and what is needed for the future. We believe that an urgent audit should be undertaken to identify the numbers and locations of specialist nurses working in Wales.

**169.** Witnesses highlighted the importance of planning the workforce based on the needs of the population, saying that this is not happening consistently across Wales. Without a clear picture of what services are needed and where, it is difficult to plan to provide those services. We believe there needs to be greater clarity around planning the workforce based on population health needs.

**Recommendation 11.** The Welsh Government should collect and publish data on specialist nurses working in Wales, including the number of specialist nurses and their locations. The Welsh Government should provide an update on the progress of implementing this recommendation to this Committee within 12 months of the publication of this report.

**Recommendation 12.** Page The Welsh Government should develop a workforce plan for specialist nurses, to ensure the future sustainability of the services they provide, with an emphasis on ensuring equal access for those living across Wales.

# 5. Mental health

## Improving mental health support for people living with chronic conditions

**170.** The need to improve mental health support for people with chronic conditions has been a consistent theme of the evidence we have heard. Evidence submitted by the Centre for Mental Health describes the "devastating impact" living with a chronic condition can have on mental health.

**171.** In February 2024, the Welsh Government launched a draft mental health and wellbeing strategy for consultation. The strategy recognises the impact of physical health on mental health and wellbeing and identifies "people with a long-term physical health condition" as an underserved group who may require additional support in protecting their mental health.

**172.** One commitment in the draft strategy is to strengthen the role and impact of ill health prevention:

> *"Welsh Government wants everyone to have long, healthy, happy lives. For this to happen we need to create the conditions that help people to look after themselves well, and we need to make sure we have the right health and social care services to help people stay well, get better when they are ill, or live the best life possible when they have problems that won't get better."*[131]

**173.** Evidence from Asthma & Lung UK Cymru states:

> *"59.9% of people told us their mental health had worsened since receiving a COPD diagnosis, with 3.8% reporting a new mental health diagnosis, 48.5% suffering anxiety and depression and 11.3% having suicidal thoughts. Yet only 20.7% who told us of the mental health impact of a diagnosis were offered mental health support from NHS Wales."*[132]

[131] Draft mental health and wellbeing strategy, February 2024
[132] CC08 Asthma & Lung UK Cymru

**174.** FND Hope UK England & Wales said that 45% of people living in Wales with Neurological Conditions (including people living with FND) felt that their mental health needs were not being met at all.[133]

**175.** One of the participants in our engagement activity told us:

> *"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."*[134]

**176.** Mind Cymru said that for many people living with a long-term physical condition, it is not the standard procedure for mental health support to be provided at the point of diagnosis:

> *"This is important as being diagnosed with a long term physical health condition can change the way in which someone perceives themselves. They may be unable to undertake activities that previously helped managed their mental health. All this can have a destabilising impact as people realise their life is likely to change."*[135]

**177.** A number of witnesses highlighted the lack of parity between physical and mental health. Participants in our stakeholder roundtable discussion told us:

> *"Physical and mental health are too often treated in silos. There is also a lack of parity between physical and mental health. Support for patients' mental health and wellbeing should be included in NHS Wales quality statements for chronic conditions."*[136]

**178.** The Royal College of Occupational Therapists (RCOT) said that mental health needs should be considered and addressed with the same priority as physical health needs. It also says that 'access to rehabilitation support for mental health needs is especially lacking'.[137]

[133] CC28 FND Hope UK England & Wales
[134] Engagement findings, June 2024
[135] CC22 Mind Cymru
[136] Supporting people with chronic conditions: stakeholder discussion 28 February 2024
[137] CC02 Royal College of Occupational Therapists

**179.** Therapies Directorate, Cardiff and Vale UHB, told us:

> *"There needs to be more joining up across services. Traditionally patients access either mental or physical health services but they are only combined in a small number of chronic condition services. Diabetes as one service area has limited access to psychology support yet there is clear evidence of the benefit of psychological support for people living with chronic conditions. The inclusion of psychologists enables us to broaden the offer to patients and meet their physical and mental health needs."*[138]

**180.** The Women's Health Wales Coalition suggested that for the most part, health and social care services in Wales are not currently organised in a way which supports an integrated response to the dual mental and physical health care needs of patients. It said:

> *"The institutional and professional separation of mental and physical health can lead to fragmented approaches, in which opportunities to improve quality and efficiency are often missed."*[139]

**181.** It went on to say that care for large numbers of people with long-term conditions could be improved by better integrating mental health support with primary care and chronic disease management programmes, with closer working between mental health specialists and other professionals.

**182.** Andy Bell, Centre for Mental Health, told us:

> *"... crucially, we need to see real investment in mental health support in physical health services for people living with long-term conditions, so that no-one is left with their emotional health and well-being overshadowed or ignored when they're living with a chronic condition, and that that support is tailored around their needs in a whole-person-care type of approach."*[140]

**183.** He said that this would require that:

> *"... your workforce in long-term condition services in physical health has at least a basic understanding of people's mental*

[138] CC33 Therapies Directorate, Cardiff and Vale UHB
[139] CC30 Women's Health Wales Coalition
[140] RoP, 17 April 2024, para 126

> *health and how to support that and how to have supportive conversations with people. Not everyone has to become a psychiatrist or counsellor, but you need that ability to do the basics, and of course that's primarily a training requirement at the beginning, but of course you then need time and you need an environment that's conducive to practise those skills."*[141]

**184.** Professor Jim McManus, Public Health Wales (PHW), said that helping people to cope with long-term conditions would require more mental health clinicians being trained in physical health, and more physical health physicians being trained up in mental health:

> *"And I think the place to start is primary care. Not by burdening primary care again, but by actually funding and supporting primary care to do the basics, mental and physical, for everybody."*[142]

**185.** Dai Davies, RCOT, argued that this training should extend to allied health professionals, so, for example, occupational therapists who work in physical health are 'dually trained'[143] so they could deliver mental health interventions.

**186.** The Cabinet Secretary said that 'a huge amount of work in relation to mental health' had been done in Wales. She also said:

> *"In a lot of our quality statements, there are sections that address the issue of the need for that person-centred approach, and, obviously, mental health becomes an important part of that."*[144]

**187.** A number of Quality Statements do recognise the impact on mental health of being diagnosed with a chronic condition. For example, the Quality Statement for diabetes says that health boards should 'provide tools and appropriate support to people with diabetes to help address the emotional and psychological impact of living with diabetes'.[145] However, Matthew Norman, Diabetes UK Cymru, warned that 'there isn't a dedicated adult service available for people living with diabetes' because it fits between physical and mental health.[146]

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[141] RoP, 17 April 2024, para 35
[142] RoP, 24 January 2024, para 155
[143] RoP, 8 February 2024, para 157
[144] RoP, 19 June 2024, para 107
[145] Quality statement for diabetes, June 2023
[146] RoP, 14 March 2024, para 187

**188.** We asked the Cabinet Secretary about support for people whose long-term condition happens suddenly, like Parkinson's or a stroke.

**189.** Using Parkinson's as an example, Dr Stuart Hackwell, Senior Medical Officer for Primary Care and Mental Health, said that his experience of Parkinson's services is that they are very holistic services:

> *"They have resources from psychologists, they have quite intensive support from Parkinson's nurses, for example, which look at that whole aspect and advise patients on how to manage their condition and help them come to terms with the degenerative condition and the general decline that's going to happen. You could use the Parkinson's model as a good model to look at other chronic conditions, especially in terms of stroke, in providing that holistic care."*[147]

**190.** The Cabinet Secretary added:

> *"I think one of the great things that we do is to use the third sector in this space as well. I think they do an incredible job in giving support, in particular that mental health support. When you think about cancer [ ], and think about organisations like Maggie's—they are there to support people with that mental health support. So, it's not just about the NHS, actually, there are broader partners that we use in that space."*[148]

## Promoting wellbeing

### Emotional wellbeing

**191.** The impact of chronic conditions on emotional well-being has been raised by a number of witnesses.

**192.** Professor Jim MacManus, PHW, said:

> *"Most people with a long-term condition will find their resilience is zapped, and the issue is: does that go into diagnosable, treatable, significant mental illness?"*[149]

[147] RoP, 19 June 2024, para 110
[148] RoP, 19 June 2024, para 112
[149] RoP, 24 January 2024, para 160

**193.** Dr Rowena Christmas, Royal College of GPs (RCGP), told us:

> *"I think many, many people with chronic illnesses have, as you say, low-grade mental health problems, and perhaps they're not even mental health problems; perhaps it's loneliness or difficulty accessing services, difficulty with transport. Often, chronic illnesses will reduce your financial ability."*[150]

**194.** Oliver John, Royal College Mental Health Expert Advisory Group Wales, advised against assuming that someone who is living with a chronic condition or an illness is permanently going to have low levels of well-being:

> *"... that's absolutely not true. I may have an illness, but I would still experience joy, happiness and the things that are important to me. I think when we consider the types of services that should be available for people to improve upon their well-being, they need to be accessible, regardless of whether you've got a chronic condition or not."*[151]

**195.** Barbara Chidgey, who responded to our consultation in a personal capacity, said:

> *"Emotional health is continually confused with mental health: I must speak up strongly to say that most people living with chronic conditions may well NOT need mental health support; first and foremost they need acknowledgement of their emotional health and conversations with trusted health professionals when they can simply say how they feel and not be subjected to merely transactional content.*
>
> *A lot of mental illness that arises from those living with long term physical illness can indeed be prevented by a stronger focus on emotional health."*[152]

[150] RoP, 8 February 2024, para 56
[151] RoP, 17 April 2024, para 59
[152] CC72 Barbara Chidgey

## Social prescribing

**196.** In January 2024, the Welsh Government published its National Framework for Social Prescribing, which sets out how it plans to provide social prescribing throughout Wales[153].

**197.** Evidence from PHW highlighted the benefits of social prescribing, which connects people to community resources and support. Zoe Wallace, PHW, told us:

> *"... at Public Health Wales we provide the national co-ordination for the service, so it is delivered in all of our 22 local authorities across Wales, but [ ] there is variation in terms of the capacity and the waiting lists, and so that's something that we need to address."*[154]

**198.** Dr Rowena Christmas, RCGP, said that social prescribing could make a huge difference, but only 26 percent of GPs have access to a social prescribing link worker.[155] [156]

**199.** Dr Hilary Williams, Royal College of Physicians (RCP), highlighted the importance of enabling people to take responsibility for their own health:

> *"I do think it's really important that we empower. And I think the social prescribing and knowing how to look after yourself can be a real game changer there. There's lots of evidence that, if we support people in the right way and with the right people, with things like social prescribing and looking after themselves, it can be very powerful. It doesn't work for everyone, but even if you get a number or a percentage of people looking after their own health, the long-term impact of that can be brilliant."*[157]

**200.** However, Lisa Turnbull, RCN Cymru, pointed out that social prescribing relies on community activities being available:

> *"So, if you don't have the community choirs or art classes or exercise schemes or any of this activity going on in the*

[153] National Framework for Social Prescribing, January 2024
[154] RoP, 24 January 2024, para 141
[155] RoP, 8 February 2024, para 56
[156] Social prescribing link workers connect people to community-based support, including activities and services that meet practical, social, and emotional needs that affect their health and wellbeing
[157] RoP, 8 February 2024, para 66

> *community, then obviously it continuously reduces the options to be able to offer the individual. [ ] So, I think there is a broader point here about how we assess and understand the impact on health, on the NHS, of some of these broader community activities."*[158]

**201.** While being supportive of the use of social prescribing, Dai Davies, RCOT, cautioned that it is a social intervention not a medical one:

> *"The important thing is that we want to ensure that when problems become such that you need to see a registered professional, the social prescribers have the training and the governance arrangements to be able to move that on. Because they're not there to treat people, they're there to socially prescribe. So, there are some concerns around that."*[159]

**202.** Dr Heather Payne, Senior Medical Officer, Welsh Government said that there were some good examples of social prescribing:

> *"We do need to rely on and engage with the third sector, voluntary organisations, through RPBs. It is happening well in some areas, such as frailty, where there are the safe-at-home exercises, but there's plenty of work for everybody in that space."*[160]

**203.** The Cabinet Secretary added:

> *"Which is why we've got this framework, because one of the key issues for me is that there are these pockets where it's working brilliantly, but one of the concerns, I think, was how do you make sure that there's a quality standard around it? How can GPs have the confidence that, when they're referring people who are quite vulnerable at times to a service, that actually the support is going to be there for them?"*[161]

[158] RoP, 8 February 2024, para 69
[159] RoP, 8 February 2024, para 162
[160] RoP, 19 June 2024, para 121
[161] RoP, 19 June 2024, para 122

## Severe mental illness

**204.** The Welsh Government report Scientific Evidence Advice (SEA) NHS in 10+ Years[162] states that adults with severe mental illness on average have a higher risk of dying prematurely from a range of physical illnesses, including respiratory disease, liver disease, cardiovascular disease and cancer. The mortality gap between those living with severe mental illness and the rest of the population is widening.

**205.** Dr Rowena Christmas, Royal College of GPs (RCGP) told us:

> *I think people with significant mental health problems will develop chronic illnesses perhaps 20 or even 30 years earlier than the population who don't have serious mental health problems, and that's partly because of the medication they're prescribed—that often increases their cardiovascular risk, it makes them more likely to be overweight or obese. They often really struggle with motivation, so they're not getting out of the house and going for a walk, they're not meeting with people, they're lonely, they're isolated.*[163]

**206.** She described the difficulties in providing healthcare to those with significant mental health conditions as 'a huge problem' that is 'something that we could do with doing better at'.

**207.** It was suggested that some professionals are not used to coping with certain patients because of the severeness of their mental health problem.

**208.** MacMillan Cancer Support says that evidence suggests that many of those with the most severe mental health needs are not receiving professional help, with only 14 percent accessing a mental health specialist.[164]

**209.** Professor James Walters, Royal College of Psychiatrists (RCP), told us:

> *"One thing we know from the research evidence—this applies to Wales, but also internationally—is that when those with severe mental illness present to physical health services,* they *get seen*

[162] Report of projections, health evidence and policy recommendations, September 2023
[163] RoP, 8 February 2024, para 61
[164] CC16 Macmillan Cancer Support

> *later, they get investigated less comprehensively and they get treated less aggressively."*[165]

**210.** Mind Cymru says that while waiting times are currently high across the NHS, treatment for both physical and mental conditions is often slow and delayed:

> *"This is noticeable in the waiting times for high intensity or specialist psychological therapies, which are designed for people with SMI. These services are usually delivered in secondary care after a primary care consultation, usually with a GP. They can be life-changing for those who need support."*[166]

**211.** It also highlighted the importance of routine physical health checks for people with severe mental illness, as recommended in our report *Connecting the dots: tackling mental health inequalities in Wales*.[167] It says:

> *"Noting that there has been an increase of the share of people experiencing SMI from 11.7% pre-pandemic to 28.1% by April 202021, the potential benefits of routine physical health checks cannot be overstated."*[168]

**212.** Professor Jim McManus said that really good physical health checks for people with severe mental ill health, and really good basic physical services, for example eye health and dental health, could really help.[169]

**213.** Professor James Walters, RCP, suggested that there should be an expectation of clinicians that there is an annual review:

> *"This used to exist in primary care for everyone with severe mental illness, but I think it should be done within mental health services. There's the capability there to do that. There's nurse training. Early intervention services for psychosis, which the Welsh Government has invested in, are really well placed to do this and have done it off their own backs, to an extent."*[170]

[165] RoP, 17 April 2024, para 40
[166] CC22 Mind Cymru
[167] Connecting the dots: tackling mental health inequalities in Wales, recommendation 4
[168] CC22 Mind Cymru
[169] RoP, 24 January 2024, para 154
[170] RoP, 17 April 2024, para 20

**214.** Dai Davies, RCOT, raised concerns around the ability of people with severe mental illness being able to access the services of Allied Health Professionals:

> *"There are hardly any dieticians, speech and language therapists, physiotherapists that actually work within mental health services. And considering the well-known problems for people who have mental health problems—10 to 15 years below the normal life expectancy, massive issues with obesity, isolation—there's a massive lack of equity between mental health patients and patients who have physical health problems."*[171]

**215.** The December 2023 update to the Welsh Government's response to Connecting the dots states:

> *"Vision Statement 4 of the new (draft) Mental Health and Wellbeing Strategy for Wales (2024-2034) specifically recognises that people who have a severe and enduring mental health conditions experience worse health outcomes. In the draft we commit to taking action to address this over the life of the new strategy and we are proposing to ensure people living with long term mental health conditions are supported in having their physical health needs met."*[172]

**216.** When asked if she thought those living with severe mental health should have an annual physical health check, the Cabinet Secretary told us:

> *"I think we've got to be driven by the evidence on that, so I'd need to look at advice on how frequently they need that kind of thing. I wouldn't want to sign up to that without further evidence that it would be exactly what has worked elsewhere, for example. But I'm more than happy to have a look at that."*[173]

[171] RoP, 8 February 2024, para 156
[172] HSC Committee, 8 February 2024, PTN 1 - Update from the Deputy Minister for Mental Health and Wellbeing to the Chair regarding the Welsh Government's response to the Committee's report: Connecting the dots: tackling mental health inequalities in Wales
[173] RoP, 19 June 2024, para 127

## Our view

**217.** There is a well-documented link between living with chronic conditions and experiencing mental health problems. Evidence suggests that at least 30% of all people with a chronic condition also have a mental health problem.

**218.** The reverse can also be true; mental health problems can limit people's ability to self-manage or engage with heath care services, exacerbating physical health conditions.

**219.** Lack of parity between mental and physical health is a long-standing issue. However, for people living with a chronic condition the impact on their mental health means there is a need for much greater integration of services. We were surprised to learn that for many people living with a long-term physical condition, it is not the standard procedure for mental health support to be clearly signposted at the point of diagnosis. Coming to terms with being diagnosed with a long-term condition and how that will change your way of life is bound to have a profound effect. We agree with witnesses that healthcare professionals working with those with chronic physical conditions need a basic understanding of people's mental health and how to support that.

**220.** Some people living with chronic conditions may need support to improve their wellbeing that falls short of needing a mental health intervention. We recognise the huge difference social prescribing can make to people living with chronic conditions. However, limited numbers of social prescribing link workers and a lack of availability to community facilities to support social prescribing is a problem. We also accept the point that social prescribing is not a medical intervention, and that social prescribing link workers need the appropriate training and resources to be able to recognise and act when the intervention of a registered healthcare professional is needed.

**221.** People with severe mental illness are the most in need of services but the least likely to get them. The Welsh Government recognises that people who have a severe and enduring mental health condition experience worse health outcomes, and has committed in the draft Mental Health and Wellbeing Strategy to take action to address this 'over the life of the new strategy'. While we welcome this commitment, we believe greater urgency is needed and would urge the Cabinet Secretary to consider the introduction of preventative, regular physical health checks for people with severe mental illness.

**Recommendation 13.** Mental health support should be signposted for all at diagnosis with a chronic condition. In response to this report, the Welsh Government should set out how it plans to implement this, and should then provide an update to this Committee in 12 months' time on progress made.

**Recommendation 14.** The impact on wellbeing and mental health of being diagnosed with a chronic condition is well documented. The Welsh Government should ensure that, as Quality Statements are developed for chronic conditions, this impact is recognised and the need for mental health support to be available is included.

**Recommendation 15.** Training on mental health should be available for all medical staff working with those with chronic conditions. The Welsh Government should provide an update to Committee in 12 months' time on work to improve mental health training provision.

**Recommendation 16.** In its response to this report, the Welsh Government should provide the Committee with an update on the implementation of the social prescribing framework, with a particular focus on how the needs of those living with chronic conditions are being met.

**Recommendation 17.** Work must be done to improve the physical health outcomes of those living with severe mental illness. The Welsh Government should review how to improve access to regular, preventative physical health checks and report back to the Committee within 12 months on the findings of this review.

# 6. Prevention

## Primary prevention

**222.** Primary prevention aims to prevent chronic conditions developing. This can be through programmes like immunisation and screening programmes, and also by identifying and addressing other risk factors.

**223.** A Healthier Wales[174] sets out 'prevention and early intervention' as a key principle to drive change. The plan promises to focus resources and workplace skills on prevention. However, witnesses raised concerns about a lack of time and resources that prevents this preventative work being effective.

**224.** Evidence from the Royal College of Occupational Therapists (RCOT) states:

> *"It's better to prevent a condition occurring/worsening, but most health services focus on reactive treatment, rather than proactive prevention and self-management. A Healthier Wales the long-term plan for Health & Social Care and other recent Welsh policy all states the need to move services to a more preventive focus but the operational reality is yet to catch up."*[175]

**225.** One element of primary prevention is addressing the determinants of health and risk factors for chronic conditions. Prof Jim MacManus, Public Health Wales, told us that most long-term conditions have the same risk factors of diet, activity, prosperity, alcohol, tobacco:

> *"... but there are also short-term things that we can do, such as early intervention, before things become difficult. The only way we're going to get out of this is by moving to a really prevention-focused system where we look at prevention not just in terms of long-term prevention, because that will take a while to deliver, but also in terms of the shorter term work that we can do, both the optimal living with long-term conditions, but also early intervention at the earliest point possible to enable people not to progress, if that is possible."*[176]

[174] A Healthier Wales: our Plan for Health and Social Care, June 2018
[175] CC02 Royal College of Occupational Therapists
[176] RoP, 24 January 2024, para 83

**226.** There are a number of preventative initiatives currently in place, including Healthy Weight: Healthy Wales (HWHW)[177] and A Smoke-Free Wales[178]. Public Health Wales are also responsible for leading the All Wales Diabetes Prevention Programme (AWDPP)[179], which supports people who are at an increased risk of type 2 diabetes to make changes to their diet and to be more physically active. In the first phase of its delivery, the AWDPP has been rolled out in at least two primary care clusters in each of Wales's seven health board areas. The programme is subject to an ongoing evaluation, which will be used to inform its design and delivery going forwards. The Therapies Directorate, Cardiff & Vale UHB, called for the programme to be rolled out across all clusters:

> *"... diabetes is the health condition that has the largest financial burden on the NHS but type 2 diabetes is largely preventable."*[180]

**227.** It also says that, with approximately 52 percent of the Welsh population being overweight or obese 'we need to look at ensuring there is adequate provision at all levels of the HWHW weight management pathway to prevent people going on to develop other chronic conditions'[181].

**228.** The Cabinet Secretary told us she thought obesity 'is probably one of the biggest threats confronting our nation at the moment':

> *"60 per cent of the population are overweight or obese. This is a time bomb, it is waiting to happen. I've already held two round-tables with international experts, coming in to give us advice on, 'What are we doing about this, have we got it in the right place?'"*[182]

**229.** She went on to say that we need to create an environment that makes it easier for people to make the right choices:

> *"So, we are just about to go out to consultation on that food environment regulation. But there's a huge amount more work to do in this space."*[183]

[177] Healthy Weight: Healthy Wales, October 2019
[178] A smoke-free Wales: Our long-term tobacco control strategy, July 2022
[179] All Wales Diabetes Prevention Programme (AWDPP)
[180] CC33 Therapies Directorate, Cardiff & Vale UHB
[181] CC33 Therapies Directorate, Cardiff & Vale UHB
[182] RoP, 19 June 2024, para 46
[183] RoP, 19 June 2024, para 47

**230.** Zoe Wallace, PHW, told us 'it'll take a long time to turn the curve before we start seeing improvements in some of our prevalence figures across Wales and that 'the NHS can't do primary prevention alone':

> *"... it's the role of local government, the local authority and the critical contribution that third sector partners provide. And we have the enabling frameworks in place in Wales through our public services boards across all of our 22 local authorities to focus on prevention and the well-being of the populations that they serve."*[184]

## Role of other sectors

**231.** Prof Jim McManus, PHW, pointed to the need for greater in investment in social care, given the role of local authorities in primary prevention, in terms of housing quality, physical activity infrastructure, clean air and good education outcomes.[185]

**232.** Written evidence from the Welsh Local Government Association (WLGA) also highlighted the range of preventative services, such as leisure centres, parks, adult education, youth work and community facilities provided at the discretion of local councils:

> *"Unfortunately, in recent years it is these services that have faced the brunt of cuts to local authority budgets as statutory services such as education and social services have been protected. It is imperative that we stem the decline of local preventative services and that we find a way to make some significant investment into new or existing preventative services based in primary and community settings."*[186]

**233.** Fôn Roberts, Association of Directors of Social Services (ADSS), highlighted the role that the third sector can play in prevention:

> *"The third sector is excellent in being able to provide prevention activities for people [...] So, it is important that we get the resources to get out to the third sector to see what they can do to support us with this early intervention and this preventative*

[184] RoP, 24 January 2024, para 191
[185] RoP, 24 January 2024, para 184
[186] CC47 Welsh Local Government Association

> *work, and I think that that is going to be at the core of our work."*[187]

**234.** Evidence from Glamorgan Voluntary Services (GVS) talked about the flexibility of the third sector to support community and statutory services where needed, but warned:

> *"It is pleasing to see that the third sector is valued and relied upon but it is not sustainable without support. Projects do not last longer than three years (enough time to establish themselves, make links, support service users and then close down). Some projects are as short as 9 months. This means that the vital experienced staff leave (sometimes leaving the sector entirely) which has a knock on effect to the organisations already struggling to retain staff."*[188]

**235.** Elen Jones, Royal Pharmaceutical Society, highlighted the role community pharmacies can play in signposting to other facilities or systems that are available to provide support:

> *"It's not always clinicians that are needed; it may be support groups, it may be third sector groups that can provide that support for patients with long-term conditions, if it's that they need to talk to people, develop a network of people that are already living with a chronic condition, for example."*[189]

## Health inequalities

**236.** The Welsh Government says that those living in disadvantaged areas are more likely to be living with multiple chronic conditions. Those who live in the most deprived areas have a shorter life expectancy and spend less of their life in good health.[190]

**237.** Professor Jim McManus told us:

> *"... there are some populations for whom the expectation that you'll get a chronic condition by the time you're 40, 50, has been normalised, and we have to change that, you know. So,*

[187] RoP, 14 March 2024, para 128
[188] CC14 Glamorgan Voluntary Services
[189] RoP, 14 March 2024, para 298
[190] Report of projections, health evidence and policy recommendations, September 2023

> *the idea that you work all your life and then you will spend the last years of your life in preventable disability and pain is something that we have to shift, and that's a cultural norm across many parts of the UK and Europe and wider. And so the early intervention will go some way to that, but, actually, what we have to do is change expectations so that people live as well as possible and age as well as possible,"*[191]

**238.** We heard that certain conditions are more prevalent in people from Black, Asian and other minority ethnic groups, for example Chronic Kidney Disease (CKD), sickle cell and Lupus. According to Kidney Care UK:

> *"Black, Asian and other minority ethnic communities are five times more likely to develop CKD, representing an unmet need that leads to a disproportionate number from these groups being represented on the transplant waiting list and waiting longer for a transplant."*[192]

**239.** Evidence from the Royal College of Physicians of Edinburgh refers to a significant body of epidemiological evidence which indicates that those from ethnic minority backgrounds may have a higher propensity to develop multimorbidity:

> *"Those from ethnic minorities can be disadvantaged in terms of socioeconomic position as a result of racism and racial discrimination, which reduces access and opportunities within employment, education, healthcare, housing, and other sectors. Access to essential services is generically focused but given the higher propensity amongst ethnic minority groups to develop multimorbidity, there are strong arguments to identify specific public health interventions to delay the onset of long-term conditions that are context based in communities."*[193]

**240.** Cardiff and Vale Therapies Directorate said the NHS and community services need to widen access to services, and ensure that culturally specific education and support is available:

> *"Health inequalities are widening and chronic conditions are more prevalent amongst ethnic minority communities and*

[191] RoP, 24 January 2024, para 125
[192] CC27 Kidney Care UK
[193] CC09 Royal College of Physicians of Edinburgh

> *deprived communities. The NHS needs to work more closely with communities and groups identified above to ensure education and support is provided in an appropriate format to meet their needs. NHS staff require training on cultural differences such as dietary practices as well as ensuring resources provided meet the needs of the population group. E.g. written resources may not be suitable even if in different languages. Audio resources may better meet people's needs."*[194]

**241.** A number of other witnesses also talked about the need to work with communities to improve take-up to services. Professor Jim McManus told us:

> *"During COVID, there was a lot of work that went on with all sorts of community groups in Wales—from faith communities to social communities and sports groups. They can be very powerful assets in supporting and enabling people to act when the food supply system is against them being healthy, and helping people to understand what they can do."*[195]

**242.** Dr Rowena Christmas also highlighted the need to build on the lessons learnt during COVID:

> *"We had people going into their mosques, or the places where they go, and increasing their health literacy there, so trying to capture them because they were less likely to present. So, it's building on that, building on that knowledge that we learnt during the pandemic to improve things now. Because you're right: they're a vulnerable group, and they're perhaps less likely to present at the doctor's surgery or come for annual checks than other people."*[196]

**243.** We heard that people living in poverty and those living with a long-term physical condition also have a higher risk of developing a mental health condition. Mind Cymru told us:

> *"Experiencing poverty; a lack of secure employment; inadequate quality or a lack of housing; facing racism and discrimination will all have a significant impact on our mental*

[194] CC33 Cardiff and Vale Therapies Directorate
[195] RoP, 24 January 2024, para 174
[196] RoP, 8 February 2024, para 93

*health. For people with long-term conditions, these factors will be felt more sharply."*[197]

**244.** Andy Bell of the Mental Health Foundation said that one of the most important things that could be done to improve the nation's mental health would be to tackle poverty and inequality:

*"We know that more unequal societies create higher levels of mental ill health, and if you take people out of poverty, if you put more income in people's pockets, particularly those who are the poorest, if you make sure that people are getting the benefits they're entitled to, supported to get work, children from the most deprived backgrounds are supported to do well in education and get a fair chance, that that will reduce the burden of mental ill health in deprived communities, and that will have a knock-on effect on physical health."*[198]

**245.** The Royal Society for Public Health told us:

*"Ensuring we have strong public services and a clear strategy to address the growing impact of inequalities on public health and support a preventative approach whilst breaking through the social and economic barriers to support those with long term conditions, is fundamental to the health of the nation."*[199]

**246.** Dr Frank Atherton, CMO, made the case for 'proportionate universalism':

*"... we need to provide good-quality services and support and prevention for the whole population. But then we need to really narrow that down and provide a more specific focus to the people who are in greatest need, and that is the way we try to address inequalities."*[200]

**247.** While Zoe Wallace, Public Health Wales, said the Welsh Government should take a 'health in all policies approach':

*"So, we recognise that long-term conditions cut across all areas of Government, all of our policies, and we need to move to a*

[197] CC22 Mind Cymru
[198] RoP, 17 April 2024, para 80
[199] CC60 Royal Society for Public Health
[200] RoP, 17 April 2024, para 187

> *position where we have health in all our policies, because it's addressing the wider determinants, education, employment, housing, which all impact on the health and well-being status and long-term conditions, so that's something that we do need to continue to systematically address."*[201]

**248.** The Welsh Local Government Association (WLGA) also said that when looking at the support needed by those living with chronic conditions it is easy to focus on the health care services that an individual receives:

> *"However, when you look at what actually makes and keeps people healthy the NHS plays a much smaller role than is often recognised. The most important aspects are things like high quality and affordable housing, access to green spaces and a good education that set people up for a long, healthy life."*[202]

**249.** The Cabinet Secretary agreed, telling us:

> *"What we know is, if you look at health, about 20 per cent of it can be managed through the NHS itself, but about 80 per cent of it is due to the conditions that people live and work in. So, obviously, there is a cross-Government approach to tackling inequality. We have done a huge amount in this space, and one of the things that is imminently going to be introduced is a health impact assessment across the whole of Government. So, whenever a new policy or piece of legislation will be introduced, it will be measured against what is the health impact of that. So, that is something that is unique. It's globally leading, and it's very much in line with the kind of future generations approach."*[203]

## Health literacy

**250.** The importance of health literacy was raised by a number of witnesses. The definition of health literacy adopted in Wales in 2010 is 'the ability and motivation level of an individual to access, understand, communicate and evaluate both narrative and numeric information to promote, manage and improve their health status throughout their lifetime'.

[201] RoP, 24 January 2024, para 90
[202] CC47 Welsh Local Government Association
[203] RoP, 19 June 2024, para 75

**251.** In her paper, *Health, Education and Prosperity for All: Wales as a Health Literacy Testbed*, Dr Emily Marchant of Swansea University, says that:

> *"International evidence suggests lower health literacy is associated with higher hospital admissions, duration of hospital stay and likelihood of readmission. It is also a key factor in the management of long-term health conditions. As such, low health literacy is a driver of higher healthcare costs and the NHS in Wales is the Welsh Government's largest area of expenditure."*[204]

**252.** She goes on to say that a significant cause of emergency hospital admissions in Wales is due to largely preventable non-communicable diseases (NCDs), and that modifiable lifestyle factors, such as smoking, poor nutrition and physical inactivity, increase risk:

> *"Health literacy is thus an important tool in the prevention and management of NCDs which are responsible for the majority of chronic diseases and nearly three quarters of deaths worldwide. Reducing the impact of low health literacy on the health service is essential and has potential in large healthcare savings."*[205]

**253.** Chris Brown, Royal Pharmaceutical Society, told us good health literacy was important for patients to understand what the future of their disease looks like and what to anticipate, and how they can be supported in self-management for that:

> *"So, people who are given an understanding of their condition, their treatments, and given access to their records and their blood results, and know how to respond to those, are supported in self-management. And I think when we support patients with self-management and with their health literacy, they become an equal partner as part of the decisions that are made about them."*[206]

**254.** Dr Nick Wilkinson, Royal College of Paediatrics and Child Health (RCPCH), agreed, saying:

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[204] Health, Education and Prosperity for All: Wales as a Health Literacy Testbed, December 2023
[205] Health, Education and Prosperity for All: Wales as a Health Literacy Testbed, December 2023
[206] RoP, 14 March 2024, para 296

> *"I think there is a huge health literacy campaign here to support our populations in understanding health better, what supported self-management is, and how to support for dementia and mental health issues. And I think that begins actually in healthcare, because I think in healthcare, we separate out mental health and physical health, and I think we all need to have responsibilities and need the tools and support and training for that across the whole of the health service to make those connections."*[207]

**255.** A number of witnesses emphasised the need for clear and understandable health messaging. Dr Rowena Christmas, Royal College of GPs, said:

> *"I read a statistic that 43 per cent of adults, if you give them written information about their health, won't understand it, and that number goes up to 64 per cent if that information includes numbers as well as words. So, we can do that better. We can provide them with information that's more understandable, or we can [ ] give them people who will help to explain it to them, and that doesn't need to be a trained medic, that can be a lower paid person who has the time to sit and explain information to them."*[208]

**256.** Similarly, the Centre for Cardiovascular Health and Ageing Research at Cardiff Metropolitan University said that health literacy has been shown to influence the ability to make appropriate health-related decisions, with low health literacy associated with lower medication adherence:

> *"A 2018 survey of British adults showed that 19.4% of respondents had some difficulty reading and understanding written health information. Furthermore, socioeconomic, and other inequalities were associated with lower health literacy: those that reported difficulty understanding health information were more likely to live in the most socially deprived quintile, have a disability or limiting health condition, lower household income or identify as being of Black Asian Minority Ethnicity."*

**257.** It also suggests that one way to improve the accessibility of health communication is by adding visuals to healthcare information, which has been

[207] RoP, 14 March 2024, para 191
[208] RoP, 8 February 2024, para 86

shown to increase comprehension and recall, particularly in those with low health literacy.[209]

**258.** Fair Treatment for the Women of Wales (FTWW) was 'concerned that public health campaigns and messaging are not always sufficiently co-produced or trauma-informed to be effective, and don't adequately consider causal factors when attempting to guide people's lifestyle choices.'[210]

**259.** The Cabinet Secretary told us:

> *"... we've got to get people to understand the consequences of their lack of engagement with their own health. There are consequences to that, which, yes, we of course will have to pick up on as a society, but there's a lot they can do to avoid it. There's a big educational piece. Some of this goes into schools, and what we need to do in schools, but there's a much broader piece, I think, for society as a whole."*[211]

## Our view

**260.** It is clear that the NHS in Wales is already struggling to cope with the demands being made on it. The predicted increase in the numbers of people living with chronic conditions will only increase this demand. Therefore a shift towards prevention is essential to ensure the long term sustainability of the health and care service. While Welsh Government health policy recognises the necessity of this shift, we believe that a combination of factors, including lengthy waiting times, and a lack of time and resources, have meant that, in reality, preventative work is often not a priority.

**261.** We welcome the inclusion in the refreshed actions to support the delivery of A Healthier Wales[212] of the promotion of "collective responsibility to maintain good health for individuals, communities and the health and social care system with a focus on preventing the onset of poor health and disease and on identifying and intervening early where disease occurs". However, this must be accompanied by a set of clear actions and targeted interventions to begin to make a meaningful difference in preventing the increasing prevalence of chronic conditions.

[209] CC35 Centre for Cardiovascular Health and Ageing Research, Cardiff Metropolitan University
[210] CC55 Fair Treatment for the Women of Wales
[211] RoP, 19 June 2024, para 47
[212] A Healthier Wales: our Plan for Health and Social Care – Action Refresh, December 2024

**262.** People living in disadvantaged areas are more likely to be living with multiple chronic conditions, and those who live in the most deprived areas have a shorter life expectancy and spend less of their life in good health. It is not acceptable that in some areas of the population, having a chronic condition at an early age is seen as 'normal'. As such, tackling inequalities must be a priority for the Welsh Government in improving health outcomes,

**263.** Certain chronic conditions are also more prevalent amongst ethnic minority communities. We heard that people from ethnic minority groups are less likely to take part in screening and preventative programmes. Much was done during the pandemic to establish relationships with community groups and this work needs to be developed to encourage and support people from ethnic minority groups to participate in their own health and care. Support and advice should be available in appropriate formats. There is also a need for training for NHS staff to ensure they understand the cultural needs of different groups and tailor services to meet those needs.

**264.** Responsibility for primary prevention cannot rest with NHS Wales alone. Wider societal determinants, such as education, housing and employment can all have an impact on physical and mental health, and affect the risk of developing long-term conditions. As such, local authorities, the private sector and the third sector all have a role to play. We welcome greater cross-governmental collaboration but more needs to be done to address these wider determinants that have an impact on health and well-being.

**265.** It is widely acknowledged that the third sector has a key role to play in supporting people living with chronic conditions. Third sector organisations can act quickly, be more agile, and respond to unmet needs that the NHS cannot address. However, the sector is experiencing huge financial pressures and funding for third sector projects can be seen as a 'nice-to-have' rather than an essential service. Short term funding for projects also causes problems with long term planning. These are not new issues, and have been raised by us, and our predecessor committees on numerous occasions. It is therefore disappointing that this longstanding issue of funding sustainability has still not been resolved.

**266.** We welcome preventative programmes such as Healthy Weight: Healthy Wales and Smoke Free Wales but believe more needs to be done to encourage people to take up these programmes. We agree with the Cabinet Secretary that there is a considerable amount of work to do to encourage people to take greater responsibility for their own health.

**267.** People who have greater levels of health literacy are less likely to rely on health services. Good health literacy is therefore important in enabling people to make informed choices about their health and lifestyle and more work is needed to promote health literacy, so people in Wales have the confidence to understand and improve their own health.

**Recommendation 18.** In response to this report, the Welsh Government should set out what action has been taken, since the publication of A Healthier Wales, to shift services towards prevention. It should also outline how the refresher actions to deliver A Healthier Wales support this shift.

**Recommendation 19.** The Welsh Government should work with partners, including local authorities and third sector organisations, to improve the connections between different sources of support for people living with chronic conditions to address broader issues beyond health, including housing, debt, and employment.

**Recommendation 20.** In response to this report, the Welsh Government should provide an update on the introduction of cross-Governmental health impact assessments and outline how they will guide policy making to address health inequalities.

**Recommendation 21.** In its response to this report, the Welsh Government should set out its current position on promoting health literacy for people in Wales.

# Annex 1: List of oral evidence sessions.

The following witnesses provided oral evidence to the committee on the dates noted below. Transcripts of all oral evidence sessions can be viewed on the Committee's website.

| Date | Name and Organisation |
|---|---|
| **24 January 2024** | **Professor Jim McManus**<br>Public Health Wales<br>**Zoe Wallace**<br>Public Health Wales |
| **8 February 2024** | **Dr Hilary Williams**<br>Royal College of Physicians<br>**Dr Rowena Christmas**<br>Royal College of General Practitioners Wales<br>**Lisa Turnbull**<br>Royal College of Nursing<br>**Calum Higgins**<br>Chartered Society of Physiotherapy<br>**Dai Davies**<br>Royal College of Occupational Therapists |
| **14 March 2024** | **Chris Brown**<br>Royal Pharmaceutical Society<br>**Dr Nick Wilkinson**<br>Royal College of Paediatrics and Child Health<br>**Dr Nicky Leopold**<br>British Geriatrics Society Wales Council<br>**Elen Jones**<br>Royal Pharmaceutical Society Wales<br>**Fôn Roberts**<br>Association of Directors of Social Services Cymru<br>**Jacqueline Davies**<br>Association of Directors of Social Services Cymru<br>**Mathew Norman**<br>Diabetes UK Cymru<br>**Sarah Jane Waters**<br>British Association of Social Workers Cymru |

| Date | Name and Organisation |
|---|---|
| **17 April 2024** | **Andy Bell**<br>Centre for Mental Health<br>**Dr Frank Atherton**<br>Chief Medical Officer for Wales<br>**Nick Thomas**<br>Welsh Government<br>**Oliver John**<br>Royal College Mental Health Expert Advisory Group Wales<br>**Professor James Walters**<br>Royal College of Psychiatrists |
| **19 June 2024** | **Eluned Morgan MS**<br>Cabinet Secretary for Health and Social Care<br>**Dr Stuart Hackwell**<br>Welsh Government<br>**Dr Heather Payne**<br>Welsh Government |

# Annex 2: List of written evidence

The following people and organisations provided written evidence to the Committee. All Consultation responses and additional written information can be viewed on the Committee's website.

| Reference | Organisation |
|---|---|
| **CC01** | An individual |
| **CC02** | Royal College of Occupational Therapists |
| **CC03** | University of Southampton |
| **CC04** | Rachael Gregory |
| **CC05** | Kathryn Tancock |
| **CC06** | Emily Griffiths |
| **CC07** | Adult congenital heart disease, Cardiff & Vale University Health Board |
| **CC08** | Asthma & Lung UK Cymru |
| **CC09** | Royal College of Physicians of Edinburgh |
| **CC10** | Gareth Evans |
| **CC11** | Alison Butler |
| **CC12** | Luan Hamilton |
| **CC13** | The Association of the British Pharmaceutical Industry |
| **CC14** | Glamorgan Voluntary Services |
| **CC15** | Christopher Williams |
| **CC16** | Macmillan Cancer Support |
| **CC17** | Ian Davies-Abbott |
| **CC18** | Hywel Dda University Health Board |
| **CC19** | Kathryn Gower |
| **CC20** | BDA Cymru Wales |
| **CC21** | Royal College of Podiatry |

| Reference | Organisation |
|---|---|
| **CC22** | Mind Cymru |
| **CC23** | British Society for Heart Failure |
| **CC24** | The Migraine Trust |
| **CC25** | Rare Autoimmune Rheumatic Disease Alliance |
| **CC26** | UK Active |
| **CC27** | Kidney Care UK |
| **CC28** | FND Hope UK England & Wales |
| **CC29** | Crohn's & Colitis UK |
| **CC30** | Woman's Health Wales Coalition |
| **CC31** | Royal Pharmaceutical Society |
| **CC32** | Health and Care Research Wales Evidence Centre |
| **CC33** | Therapies Directorate, Cardiff & Vale University Health Board |
| **CC34** | David Proud, Clinical Dietetic Lead Cystic Fibrosis Service |
| **CC35** | Centre for Cardiovascular Health and Ageing Research, Cardiff Metropolitan University |
| **CC36** | Welsh National Opera |
| **CC37** | Sport Wales |
| **CC38** | Moderna |
| **CC39** | Royal College of Paediatrics and Child Health |
| **CC40** | NHS Executive All Wales Diabetes Implementation Group and Cardiff & Vale UHB |
| **CC41** | Dee Montague-Coast |
| **CC42** | British Geriatrics Society Wales Council |
| **CC43** | An Individual |
| **CC44** | Learning Disability Wales |
| **CC45** | Royal College of Nursing Wales |
| **CC46** | Royal College of Psychiatrists Wales |
| **CC47** | Welsh Local Government Association |
| **CC48** | Hereditary Anaemia Service for Wales working under Cardiff and Vale Health Board |

| Reference | Organisation |
|---|---|
| **CC49** | Boots UK |
| **CC50** | Alzheimer's Society |
| **CC51** | MS Society Cymru |
| **CC52** | National Axial Spondyloarthritis Society |
| **CC53** | Arthritis and Musculoskeletal Alliance |
| **CC54** | British Psychological Society |
| **CC55** | Fair Treatment for the Women of Wales |
| **CC56** | Centre for Mental Health & Kidney Research UK |
| **CC57** | Marie Curie |
| **CC58** | Royal College of Physicians |
| **CC59** | Society of Occupational Medicine |
| **CC60** | Royal Society for Public Health |
| **CC61** | EPP Cymru |
| **CC62** | Cross Party Group on Women's Health |
| **CC63** | Kidney Wales |
| **CC64** | RNIB Cymru |
| **CC65** | Chartered Society of Physiotherapy |
| **CC66** | Kayleigh Cooper |
| **CC67** | An individual |
| **CC68** | Long Covid Wales |
| **CC69** | Royal College of General Practitioners Cymru Wales |
| **CC70** | Community Pharmacy Wales |
| **CC71** | Older People's Commissioner for Wales |
| **CC72** | Barbara Chidgey |
| **CC73** | All Wales Diabetes Patient Reference Group |
| **CC74** | Versus Arthritis |
| **CC75** | Pfizer UK |
| **CC76** | Public Health Wales |
| **CC77** | Diabetes UK Cymru |

| Reference | Organisation |
|---|---|
| **CC78** | ADSS Cymru |
| **CC79** | Katrina Owen |
| **CC80** | Cerebral Palsy Cymru |
| **CC81** | Auditory Verbal UK |

## Additional Information

| Title | Date |
|---|---|
| Additional information from the Centre for Mental Health | 29 April 2024 |
| Additional information from the Royal College of Nursing Wales | 29 April 2024 |
| Additional information from Terrence Higgins Trust Cymru | 28 March 2024 |
| Additional information from Mind Cymru | 21 March 2024 |
| Additional information from Auditory Verbal UK | 11 January 2024 |