

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC55: Ymateb gan: | Response from:  
Fair Treatment for the Women of Wales (FTWW)

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## **FTWW Response to Senedd Health and Social Care Committee Inquiry:**

### **Supporting People with Chronic Conditions**

**Fair Treatment for the Women of Wales (FTWW) is a patient-led charity and disabled people’s organisation (DPO) focused on female health equality. We support and advocate for women and people assigned female at birth who are disabled and / or living with long-term health conditions in Wales.**

FTWW hosts a pan-Wales online community with whom we shared the details of this inquiry. The following evidence constitutes some of our members’ responses to the questions posed by the Committee, alongside a summation of previous research findings, publications, and dialogue undertaken with both community members and FTWW’s wider network. It is perhaps worth pointing out that the topic of this inquiry has resulted in some of the most passionate and powerful testimonies we have encountered. They have come from respondents living with a wide and diverse array of health issues and circumstances, demonstrating the far-reaching impact and importance of this topic for the Committee’s consideration.

## **1) NHS and social care services**

### **1a) The readiness of local NHS and social care services to treat people with chronic conditions within the community;**

Whilst it is vitally important that citizens' local NHS is able to support people with chronic conditions within the community, our members have long emphasised the equal importance of their being enabled to access more specialist services outside of their own health board should they not be available locally. Despite the prevalence and impact of some of the health conditions with which our members are living, historical lack of investment in research, and a widespread failure to prioritise those conditions predominantly or disproportionately impacting on female health, has resulted in patchy service provision across Wales.

Our members are concerned that there is an unrealistic focus on 'care closer to home' which does not adequately reflect their wish to choose a more specialised service. The wholesale commitment to this approach denies them 'voice and control' in decision-making around their healthcare, prevents them from accessing optimal care in a timely fashion, and potentially reduces their chances of better health outcomes and being able to fulfill their potential in life. Typically, Welsh Government health policy documents state that 'care closer to home' is the preferred option for patients but, in a 2022 survey of its members, FTWW found that the vast majority would be prepared to travel out of area for more specialised care for their condition(s), with 100% of respondents telling us they had never been offered the choice.

Lack of access to specialist care has further consequences: it can lead to delayed diagnoses which, in turn, can result in lack of access to appropriate support and reasonable adjustments at work, often leaving people with no option but to leave employment. Despite the Welsh Government's commitment to the social model of disability, the medical model still predominates in workplaces and in UK legislation, policy, and practice. Without a formal diagnosis, therefore, those affected are left struggling with

unexplained symptoms and a failure to appreciate their rights as outlined in the Equality Act 2010. Ironically, disabled and chronically ill people, at higher risk of poverty as a result of not being able to work, can find themselves having to pay privately for the diagnosis and treatment they need, exacerbating financial difficulties.

Nevertheless, beyond specialist services, there is still very much a need to provide interim and ongoing care locally for patients living with chronic and fluctuating health conditions. Even with the commitment to care closer to home and evidence demonstrating the benefits of certain therapeutic interventions, there remain seemingly arbitrary 'rules' which can prohibit patients from accessing local services such as pain management. Fibromyalgia patients report being denied access to local pain clinics or physiotherapy, with primary care practitioners equally frustrated that they are unable to act in the best interests of their patients.

Even when guidance allows for patients to be referred into local therapeutic services, there can often be insufficient capacity to cope with demand: pelvic physiotherapy services are a good example of this. Whereas other types of physiotherapy services have enough personnel to allow patients to self-refer (for back, knee, or shoulder pain, for example), the same does not apply to patients who require support to manage pelvic pain and / or scar tissue from previous operations (including hysterectomies and, in some instances, c-section births). The result is that many patients, despite living with increasing impairment that may be impacting on their ability to work, are forced to pay privately to help them 'self-manage' their symptoms and regain some degree of quality of life.

**Our members tell us:**

*'I'm a Teacher with Endometriosis, long COVID and autonomic dysfunction. I am heading towards dismissal on the grounds of ill health. I qualify for PIP and blue badge. My experience of NHS has been disjointed and left me with more questions. I have had to pay a private cardiologist for answers about my heart issues. I have had to research and pay for private gut testing, private B12, join*

*clinical trials etc. I'm now on NHS Long COVID rehab online but doesn't look like I will see an actual person face to face'.*

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*'There basically is no readiness or ongoing treatment. The NHS refuse to even acknowledge Mast Cell Activation Syndrome / MCAS is a real condition, let alone diagnose or effectively manage it...The NHS in Wales is appalling at diagnosing autism in women and non-binary people, leaving me to seek a private diagnosis. The waiting lists for gynae have historically been so long that I went private for that treatment'.*

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*'Since I was diagnosed with ME, I have received zero follow up from the GP surgery which has been a disappointment, as it is a life-changing diagnosis requiring support. The help I have accessed, via the Council and Independent Living Services has been pursued by me and my husband, with no input from the GP. When I was very ill with ME earlier in 2023 and totally bedbound, my family insisted on calling the GP to request a home visit. My mother-in-law was told by a GP that home visits are only for terminally ill and elderly patients, and that seeing me would be "a waste of resources". Therefore I haven't seen any evidence of NHS willingness to treat people in the community if they are not elderly or life-limited.*

*My husband and I don't believe that the NHS locally are interested in engaging with my ME as it cannot be cured, or treated like other illnesses can with medication. I feel as though they are happy to leave me to be bedbound or housebound for years with no support in the community. On the other hand, the occupational therapist from the council, and independent living, were very helpful and supportive, and the council came out to install aids in my home very quickly'.*

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*'I have only ever found unwillingness and passing the buck when I attempt to get support from the NHS, Police, Citizens Advice, local councils, Welsh Government etc. If they can refer you to somebody else, they feel they have done their job. This is clearly untrue and is not dealing with the problem, simply giving it to someone else and hoping they get away with it'.*

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*‘Pelvic physiotherapy has been hugely beneficial for my endometriosis management (including post-surgery scarring/adhesions) and bladder and bowel issues...I was declined pain management support initially because the locum GP I spoke to failed to cite endometriosis as well as fibromyalgia as a source of pain on the referral. Pain specialists won’t see fibro patients’.*

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*‘There is no real treatment, only management of symptoms. Granted, there are many conditions that see society disable us that have no real treatment options but none of the helpful stuff, like therapeutic art classes etc, last longer than six weeks. Pain clinic can be summarised thus: Lose weight and go for a walk. Absolute rubbish. What we wanted was how to manage our pain’.*

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### **1b) Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people**

Women, girls, and those assigned female at birth (AFAB) make up 51% of the population in Wales. Despite this, our members have made clear to us that they don’t feel that healthcare services meet their needs. Traditionally, symptoms associated with ‘women’s health’, particularly but not exclusively gynaecological conditions, are, somewhat incongruously, either taboo or ‘normalised’, so that those affected feel that they can’t describe openly how symptoms are affecting them and, when they do, the impact is underplayed or dismissed.

At the same time, internalisation of societal attitudes means that many women describe themselves as ‘downplaying’ the impact of their symptoms, feeling that they should be more stoical and ‘just get on with it’. All of these factors contribute not just to diagnostic delays for a whole host of health conditions, it has also led to a lack of research, lack of treatment options, and inadequate investment in suitably specialised service provision. This extends across Wales in terms of ‘women’s health’ services and also to the care of diseases which impact both males and females, with the latter experiencing comparatively poor outcomes.

Whilst laudable in its ambition to achieve person-centred care, the Welsh Government’s existing strategy for health and care in Wales, ‘A Healthier Wales’, does not adequately consider substantive pre-existing inequalities

which prevent its being a reality for many groups in Wales, not least women living with chronic health conditions. We are pleased therefore that, in line with its commitment to being a 'feminist government', officials have listened to calls for a co-produced NHS Wales 'Women's Health Plan' to address intersectional inequalities which have had such a devastating effect during and beyond the pandemic. However, we would call on the Committee to continue its monitoring of progress in this regard, not least to ensure that patients and public are fully involved in the plan's development, and that implementation takes place equitably and in a timely manner.

As acknowledged in the Women's Health Wales Coalition's 'Quality Statement for the Health of Women, Girls and those Assigned Female at Birth', which FTWW co-Chairs, historical prejudice and unconscious bias around women's reporting of symptoms can see patients dismissed or disbelieved, and this can extend time to diagnosis.<sup>1</sup> Such prejudice and bias is even more pronounced for women from a Black or ethnic minority background. Their intersectional<sup>2</sup> identity means that they are more likely to experience inequalities both in accessing healthcare and in health outcomes, as they identify with more than one group that disproportionately face health inequities in the UK.

FTWW notes that, when it comes to chronic health conditions which affect both sexes, diagnostic criteria and treatment are often based on the male experience, largely because clinical guidelines are often based on a 'typical' male model. This contributes to reports of women's symptoms being overlooked or dismissed. Many of our members tell us that their physical issues are regularly misattributed to underlying 'anxiety' or depression, but that, in fact, any effect on their mental health has come about subsequently, with patients describing feeling depressed as a result of living with unexplained physical health problems and anxious because they don't feel as though they are being taken seriously by their wider networks or their healthcare providers. One telling example of this is in how pain is treated, a symptom often associated with chronic health conditions: evidence suggests that women wait longer than men for pain relief and are more likely to be given sedatives instead.

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<sup>1</sup> [Women's Health Wales: A Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth.](#), (2022), p.83.

<sup>2</sup> Intersectionality, a term coined by Kimberle Crenshaw in 1999, illustrates that people's identities can overlap and essentially accumulate, further compounding their experiences of discrimination. See: UN Women., (2020). [Intersectional feminism: what it means and why it matters right now.](#)

Our members have reported further intersections which compound inequality in both accessing and receiving optimum care. These include:

- having physical and mental impairments or pre-existing diagnoses which can 'overshadow' reporting of new issues and / or make it difficult to access services which accommodate people's specific needs
- having a learning disability
- being neurodivergent
- having additional communication requirements (including not speaking English or Welsh as a first language)
- gender identity and sexual orientation
- being in a position of socio-economic disadvantage.

Unconscious biases on the part of health and care providers often lie at the root of the inequity experienced by the individuals affected, with social, cultural, and historical perceptions influencing how they are perceived and treated, and a limited appreciation of the need to positively address the barriers that individuals face or, indeed, how.

As already mentioned, the medical model of disability continues to predominate in people's conceptualisation of disability, with healthcare and welfare systems usually requiring people to have a 'diagnosis' or fit a very narrow (usually clearly physically visible) definition of the term. For those who are living with invisible and / or fluctuating chronic conditions where diagnosis may well take years, this poses a significant barrier to support or feeling equipped to pursue one's rights, such as reasonable adjustments in the workplace.

Within the parameters of the Equality Act, many members of FTWW would be perfectly entitled to describe themselves as disabled but either don't believe they 'qualify' and that they should be enduring their symptoms without complaint, or that to describe themselves as such leaves them open to discrimination. These barriers make it difficult to accurately collect data on disability, and they also make it difficult to ensure that services meet different people's needs. It also underlines the importance of early intervention in people's healthcare journeys: many of our members have become increasingly disabled as a consequence of not having their symptoms identified, taken seriously, and treated optimally, earlier on.

When it comes to specific barriers to disabled people accessing health services, various issues have been reported to FTWW, including:



- Not being able to get to the location where those services are situated; public transport is rarely fully accessible or available
- Information provided to patients may not be provided in accessible formats
- Health service staff will not necessarily have undertaken or embraced disability equality and social model of disability training or be cognisant of the multifarious ways in which disability manifests
- Physical spaces in which appointments and interventions are provided may not be equipped or appropriately managed to cater for disabled people's different needs
- Limited opportunities for disabled people to engage co-productively with health service providers in the design and delivery of services.

The result of any or all of the above can be increased impairment and trauma. At FTWW, we believe that social model of disability training, alongside work on identifying and challenging unconscious bias, should be mandatory for all healthcare providers and professionals and that training should be designed and delivered by people with lived experience, including of chronic illness.

As briefly outlined in section 1a, one key factor in many patients' deterioration and increasing impairment is systemic in origin and centres around how the seven health boards in Wales are funded. It is important for the Committee to appreciate that whilst ongoing support, monitoring, and management of chronic conditions should be available close to home (and, in some instances, technology can assist with this), a significant number of those living with chronic and recurrent health issues also need to be able to access more specialist services, especially when those conditions are complex, or less commonly diagnosed. Unfortunately, the block-funding system for healthcare in Wales can often act as a barrier to person-centred care, with funding not following the patient, therefore preventing them from accessing the most optimal care for their condition.

Whilst the origin of Wales's block-funding arrangements was undoubtedly to ensure equality of access, in practice, it means that more complex, highly specialised, and 'expensive' care, usually only available in one or two health boards in Wales, or across the border in England, is often not offered to patients from outside of those locations as it is not financially viable for providers to absorb the costs associated with offering the service to 'out of area' patients. The result is a postcode lottery which must be addressed by the

new NHS Executive in Wales if we are to eliminate the current variation and inequality which sees some patients better-served than others.

Whilst recent Welsh Government strategies increasingly call on health boards to ensure ‘regional collaboration’ in their approach to service delivery, patients report still not seeing this in practice, so it is incumbent upon decision-makers in Wales to re-examine how the healthcare system in Wales is funded and operationalised if we are to see real and positive change. Amongst those conditions mentioned frequently within FTWW’s community are severe / extra-pelvic endometriosis, premenstrual dysphoric disorder, autoimmune conditions like lupus, and connective tissue disorders like Ehlers Danlos Syndrome, all of which should have access to more specialised care in line with national / international recommendations.

Patients living in rural parts of Wales are particularly badly affected by barriers to optimum healthcare. Not only are they more vulnerable to the isolation, mental health, and socio-economic impacts that can go hand-in-hand with a chronic illness, they also face limited access to information, services and support compared to those living in urban areas.<sup>3</sup> This is especially true for ethnic minorities and disabled people living in rural parts of Wales, as access to health and care services is more difficult, and the scope of those services is more likely to be limited. When it comes to localised support in rural communities, it is less likely to be culturally competent or sufficiently flexible to accommodate various impairments. The result is that ethnic minority and disabled people don’t trust or feel able to access such services, making effective management close to home more difficult to achieve<sup>4</sup>:

### **Our members tell us:**

*‘The diagnostic delay caused my ME and fibromyalgia, bladder issues and permanent damage to my bowels...Block funding causes barriers to care rather than empowering services and patients, and there is no urgency to amend this’.*

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<sup>3</sup> Race Equality First., (2021). [Joint NGO Shadow Report on Racial Inequality in Wales.](#)

<sup>4</sup> *Ibid*

*'On top of the endless roadblocks just to get any care at all, there's then the double discrimination being part of minority groups and chronically ill poses. From being endlessly disbelieved, condescended to, and ignored, which I'm sure is at least in part because I'm not a man; to the barriers disabled people face such as absolutely no workarounds to access for people with ME whose sleep schedules are unpredictable, the demand for in person appointments even when they aren't necessary, highly scented medical environments (a trigger for Mast Cell Activation Syndrome / MCAS), and more; to the casual discrimination of my partner always being assumed to be my carer/friend, presumably a combination of me using a wheelchair and her being a woman...'*

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*'The insistence on naming various gynae services "women's...". This puts an instant barrier in the way of trans, non-binary and intersex people with gynae systems but who aren't women, from getting care.'*

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*'(I have) felt so dismissed by doctors when I've been desperately trying to get what I need. I really have felt 'judged' to be a hysterical, over-anxious female. The anxiety exists from years of physical torment and neglect.'*

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*'My experience with a range of consultants and other practitioners in the past couple of years has been abysmal, even worse than previously. Only a few of my health concerns have been addressed, instead valuable time has been spent pinning my problems on so-called 'health anxiety'. Massive assumptions have been made about my mental health and how trauma must be the reason for my pain and fatigue. I'm 56 and highly educated, yet I've been talked to like a 12 year old.'*

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*'Having debilitating symptoms viewed as "typical women's problems", told for over 2 decades (that) painful periods, heavy continuous bleeding, pain whilst defecating, ovulating or urinating are all a normal part of being a woman, then was chastised for even mentioning them. Only got a diagnosis of stage 4 endo when I pursued things privately.'*

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*'I was forced to pay privately for diagnosis – NHS consultants who performed two laparoscopies were not appropriately trained and told me I had IBS. A specialist team is based less than ten miles away from my home, yet I was refused any referral to them – despite my symptoms fitting the pathways according to NICE guidelines'.*

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*'My doctor's tried to take me off register because I was homeless and only because I made a complaint to primary care did they keep me on which has now made me not want to go to doctors'.*

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*'I am a disabled woman. Using the telephone is inaccessible for me and it takes me around two hours to get up and be coherent each day due to the symptoms of my impairments. Yet the only way I can get an urgent GP appointment is to join telephone roulette at 8am and sit on hold for about 30 minutes, usually to be told that the appointments have gone. Appointments are either in-person (which causes me additional pain and fatigue and means my husband has to take time off work to take me to them) or over the phone. In 2023, especially after the global pandemic where the world moved online, you would think it possible to have more medical appointments over video calls'.*

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*'Physiotherapy wanted to send me on a course for strengthening muscle groups. I can't get there. Transport links are awful and they don't really deal with wheelchair users. What I need is a formal diagnosis of Ehlers-Danlos and not just to be told, "yeah, you are really hypermobile"...My hysteroscopy was arranged quickly but I was called "mildly autistic" and told that "my lot" handled pain better when I should have been offered a local anaesthetic'.*

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### **1c) Support available to enable effective self-management where appropriate, including mental health support**

Many of our members report to us that they are expected to 'self-manage' by default, regardless of whether there is any local – or appropriate – support to

do so, largely because formal healthcare services, as delivered by healthcare professionals, are over-subscribed, unavailable, or inaccessible.

Mental health support, even for those with confirmed mental health conditions and psychiatric disorders, is patchy, with excessive waiting times, insufficient numbers of suitably qualified clinicians, and restrictive referral pathways which prevent access to specialist services. Patients with moderate to severe mental health needs find themselves forced to self-manage, sometimes with some limited support provided within local primary care. Efforts to refer these patients for more specialist intervention or therapies within secondary care are often unsuccessful as there are not enough staff to offer them support in the longer-term. The result is that they are bounced-back to primary care and can remain in this state of limbo for many years, with limited chance of recovery as a result.

Whilst the situation remains as it is, the suggestion that the limited care on offer be even more stretched to accommodate patients whose primary diagnosis is physical in nature is not practicable. This is despite the fact that many patients would welcome mental health support to help them cope with the debilitating impact of chronic pain, fatigue, and / or other symptoms on their psychological wellbeing and lives. This was clearly evidenced in 2020's All-Party Parliamentary Group for Endometriosis report which, in a survey of over 10,000 patients across the UK found that the condition was impacting, 'all aspects of life, including education, career, relationships and social life, as well as mental health, with 95% saying that endometriosis / the symptoms of endometriosis had impacted their wellbeing negatively or very negatively and 89% describing feeling isolated due to their condition. 90% would have liked access to psychological support, but were not offered it'.<sup>5</sup>

### **Our members tell us:**

*'It's hard to get proper diagnosis and barely any services for ongoing treatment in Wales. (It) took 2 years after being diagnosed with endometriosis to actually*

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<sup>5</sup> <https://www.endometriosis-uk.org/sites/default/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>, page 7

*be told I had it and no support after. (It) took another 3 months to be diagnosed with psoriatic arthritis and there's no support currently in Newport South Wales for that and also being diagnosed with depression and then waiting months for appointment with primary care...My current situation has me seriously depressed'.*

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*'Mental health is MASSIVE for me particularly being diagnosed with endo so young and the lack of support around it. I was sent to a mental health nurse who did nothing for me. I also phoned 111 mental health support last week as my doctors was closed for a training day and really needed support, they told me they'd refer me to the primary care team but waiting lists are BEYOND. There should a million percent be extra mental health support for the likes of us living with chronic/ multiple illness. There is NO mental health support as it is but even less for those with chronic illness that effect so much of everyday life'.*

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*'By the time I get my new bathroom and stair lift, it will have taken 18 months. During this time my pain and ability to get up the stairs has worsened and this is because I still have to go up the stairs. I have been using a stool that I bought as a halfway measure and I was told not to use it as it was dangerous and given a bath board. I had reservations and voiced them because my bath is old and moulded and was told it would be fine. It collapsed under me and I was injured. I pointed this out to the OT (Occupational Therapist) and was told to strip wash until I got my new bathroom. This was 8 months ago. They tried to make me have a commode rather than a stair lift. They would send someone in to empty it daily. Because that is how independence works right? Mental health services are non-existent. If I wasn't getting counselling through my university I would not be here'.*

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## **2) Multiple conditions**

**2a) The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation**

There is an assumption that patients have the capacity, skill, and ability to navigate what can be complex care pathways themselves, a particularly insidious issue when patients are dealing with multiple conditions, numerous healthcare professionals, and various service providers. At present, there appears to be no universal mechanism in Wales to offer patients in these circumstances care co-ordinators, navigators, or equivalent, although this is a key recommendation from the CONCORD mixed-methods study, published in 2022<sup>6</sup> which we hope to see properly considered going forward.

Without this type of provision, patients with additional learning needs or without a wider support network, on top of symptoms which may impair cognitive function and energy levels, can find themselves excluded from healthcare systems. The traditional conceptualisation of the GP as the patient's care co-ordinator, personally assisting patients with their individual queries and concerns about pathways, test results, treatment options and contraindications, is no longer a reality for many of FTWW's members. This has been further compounded by the pandemic with General Practice now even more over-stretched and inaccessible to those with various impairments.

In North and West Wales, GP Hub Wales<sup>7</sup> is being offered as a measure to assist some practices who are struggling with staffing and sustainability. The Hub enables them to utilise GPs with more capacity in Cardiff to provide remote consultations, prescriptions, and referrals for patients in affected areas. Whilst this certainly seems to be a pragmatic solution, FTWW wonders how far GPs based in far-removed parts of the country are able to provide a person-centred approach, ensuring patients access the most appropriate – and optimum – care, when there can sometimes be a lack knowledge of pathways, personnel, and services even on a local basis?

A long-standing issue, preceding but compounded by the pandemic, is the short duration of GP appointments and the fact that patients usually do not have access to the same GP (or other healthcare professional) at each

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<sup>6</sup> <https://www.ucl.ac.uk/epidemiology-health-care/research/applied-health-research/research/health-care-organisation-and-management-group/concord>

<sup>7</sup> <https://gphub.org/About-Us-FAQ.php>

appointment. Whilst there are undoubtedly a number of reasons for this which usually lie outside of the GP's individual control, the impact on patients with long-term conditions and multi-morbidities is considerable: it means they are often required to repeat symptoms and encounter care pathways which are fragmented and convoluted. At best, the experience is frustrating and disempowering, at worst, constant repetition of symptoms / issues can be traumatising and lead to a worsening prognosis. As technology is further embedded into our healthcare systems, there are hopes that the NHS Wales App (for patients) and Wales Clinical Portal (for healthcare professionals) will help with the recording, monitoring, and communication of symptoms and treatment but we must be mindful that these technologies cannot replace proper 'relationship-based' care, especially for patients who are digitally excluded.

Across the UK and in Wales, healthcare is often delivered in such a way that patients often describe their primary care appointments as 'gate-keeping' as much as anything else. FTWW members recount being referred for only one intervention / test / procedure / specialism at a time, with long waits between individual appointments and results before they can be referred to the next. This makes holistic care almost impossible and patient journeys to the 'right' diagnosis and care long and protracted. Patients with complex / inter-relating issues and conditions tell us that they can quite feasibly spend years going backwards and forwards to different departments who rarely, if ever talk to one another in any meaningful way to establish treatment plans which don't conflict with one another. Clearly, where patients with chronic conditions and multi-morbidities are concerned, multi-disciplinary approaches and regional collaboration is absolutely essential but there doesn't appear to be the time, capacity, funding, or logistics to routinely offer such an approach. We hope that, in this regard, technology can be utilised to assist with making cross-specialism communication possible, not least where providers are far-distant from one another.

Another issue reported to FTWW is that of 'Shared Care Arrangements' in Wales. This is where, 'primary care accept the transfer of prescribing responsibility from specialist care, for medicines that require long-term regular



monitoring'<sup>8</sup>. For a not insignificant number of patients across the UK, with Wales no exception, this specialist care has been self-funded for various reasons, including escalating waiting lists, lack of specialist personnel locally to make a diagnosis, and difficulties accessing optimum treatment.

As suggested in section 1 of this submission, women seem to be particularly at risk of finding themselves in this situation. Partly, this is because 'benign' gynaecology services have been the most severely impacted by pandemic-related reprioritisation of care<sup>9</sup> (perceivably because the symptoms associated with 'benign' gynaecological issues are widely considered not to be as 'serious' or life-impacting as others). Alternatively, for less commonly diagnosed conditions, like lupus or EDS, the specialist care required either doesn't exist in Wales, is located 'out of area' (and therefore unavailable to patients in other health boards) or is vastly over-subscribed. Having self-funded, patients have reported to FTWW that they then find that there is no guarantee of their diagnosis or treatment plan being accepted for a 'shared care arrangement', even when the specialist(s) providing the information are the same ones as are operating in the NHS.

As mentioned, a good number of the problems described above apply to patients across the UK not just in Wales, but, nonetheless, it is important for the Committee to appreciate that, regardless of location, many of those who have found themselves in this predicament are not wealthy but have gone into debt to 'go private' because they felt they had no other choice<sup>10</sup>. At FTWW, we are extremely concerned to hear from patients who feel as though they are being 'punished' for pursuing this avenue, describing their diagnoses as being dismissed and prescriptions not filled, not least because it results in increasing impairment for the individual and further costs to the public purse.

It is also important to point out that it is not only patients who have turned to private providers who find themselves in this predicament. We also hear from

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<sup>8</sup> <https://awttc.nhs.wales/medicines-optimisation-and-safety/medicines-optimisation-guidance-resources-and-data/prescribing-guidance/shared-care-prescribing-and-monitoring-guidance/>

<sup>9</sup> <https://www.rcog.org.uk/about-us/campaigning-and-opinions/left-for-too-long-understanding-the-scale-and-impact-of-gynaecology-waiting-lists/>

<sup>10</sup> <https://www.bbc.co.uk/news/uk-wales-62169492>

patients whose primary care providers have been reluctant to undertake these arrangements with NHS specialists. Sometimes this is because they 'do not feel they can accept responsibility, or they feel insufficiently competent'<sup>11</sup>, and sometimes because they don't agree with the diagnosis or plan. Patients tell us they are left confused and anxious. We would like to see 'Shared Care' arrangements and processes improved and streamlined so that those patients can be assured that their care will be appropriately managed going forward and 'close to home' if that is their preference. It may be that this requires an increased focus on specialisation in general practice and across clusters, including sharing of GPs with a 'special interest' and additional qualifications in certain conditions, and increased investment in the recruitment and training of advanced skills nurses.

#### **Our members tell us:**

*'(I have) had to push, literally over several GP appointments, to be referred to different specialists to deal with my array of symptoms and basically diagnos(e) myself and lead them to the correct specialists instead of being able to trust their opinions and expertise. Since being diagnosed with HEDs, POTS & Chronic Status Migraines I have to keep joining the dots and refer NHS providers to my different chronic conditions and how their individual treatment plans may counteract treatments put in place by other doctors which is both physically and mentally draining'.*

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*'A diagnosis of ME from the GP as rheumatology said they wouldn't be able to do anything for me. Zero further support from anyone. No one from GPs to specialists being able to do anything to support any of my many debilitating conditions and symptoms, even at an initial stage, let alone ongoing. Literally the only support I have for anything is my wonderful POTS consultant who is a real outlier in the care he gives'.*

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*'I have been accessing the NHS for many serious conditions since I was aged 12 in 1999, and in locations all over Wales, but I have never felt that the NHS treats me as a whole person with various health needs. Rather I am treated as*

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<sup>11</sup> <https://awttc.nhs.wales/files/guidelines-and-pils/shared-care-prescribing-and-monitoring-guidance-pdf/>

*different body parts, organs or illnesses in isolation. I don't believe the NHS is set up to respond to people with multi-morbidities without major reform, although I would feel much more respected and happy as a patient if it were. Appointments where I am told there isn't time to discuss that issue, or not to talk about this illness, is draining and disheartening'.*

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*'Feeling nobody was able to see my body holistically. Having had a range of comorbidities and manifestations from chronic conditions for 45 years has been difficult. One would hope the GP could do this but the resources aren't there for them to discuss more than one thing, more than for a few minutes. It leaves patients feeling helpless and desperate....which easily leads to (the interaction between mental health conditions and long-term physical health conditions) and the medics and how they view a patient who is frustrated, anxious and depressed at their futile struggle to achieve a cohesive treatment plan'.*

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*'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 (that's if there's a willingness to see me at all, which there often isn't). Even down to the level of GP, you can only talk about one, maybe two things per appointment, there is never time to actually deep dive into what's wholly wrong with you. That is if you can even get an appointment, which are like good dust nowadays...I've given up trying to get any proper care for any of my problems for the most part. There just is no structure within the NHS to support me'.*

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*'Conditions are treated in silos with no patient-centred care and no shared decision making (the latter in breach of NICE guidelines). I have been given standard advice leaflets for one condition with no recognition that if I follow the advice given, it might make other conditions worse'.*

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*'People are denied treatment for one condition because having another makes them 'complex'. So many conditions are co-morbid, but you can get treatment for one or the other. Choose which is worse, well I can't. They impact on each*

*other so much. So I have treatment for fibromyalgia but not EDS. I have antidepressants for my depression but no EMDR (Eye Movement Desensitisation and Reprocessing) for my PTSD (Post-Traumatic Stress Disorder). Don't even start me on the impact my Alexithymia has on my Autism and ADHD (Attention Deficit Hyperactivity Disorder). I am getting no help for any of them'.*

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## **2b) The interaction between mental health conditions and long-term physical health conditions**

It is important to bear in mind that, just like physical health conditions, mental health conditions can be similarly chronic and / or fluctuating in nature. As a disabled people's organisation, FTWW supports and advocates for people living with either or both and this submission reflects that.

Unsurprisingly, there is a complex interplay between mental and physical health issues and conditions – either one can cause and impact upon the other. As a society and in healthcare services there is a tendency to view them as distinct, which can do patients affected a considerable disservice. Lack of / delayed diagnosis and appropriate support for either mental or physical health issues, or neurodivergence, can compound problems and exacerbate symptoms, increasing the possibility of developing additional multi-morbidities. Prevention / early intervention in all of these areas is key, and that means listening to patients and working with them to identify their priorities and needs so that care is tailored to them rather than expecting patients to fit into pre-determined 'boxes' where type and location of services are concerned. Whilst it is vital that systems in Wales ensure access to healthcare is equitable, with reduced variation in availability, accessibility, and standards of care, at the same time, patients need to know that their individual care will be sufficiently flexible to suit their needs and priorities, and make person-centred care a reality.

As with physical health conditions, FTWW members have reported being unable to access specialist mental health interventions within their locality and being denied referrals to out of area services, including dedicated in-patient

settings like those offered elsewhere in the UK for eating disorders, peri-natal mental health, or severe Obsessive Compulsive Disorder (OCD). Whilst low-level interventions like telephone helplines, online short-duration Cognitive Behavioural Therapy (CBT) or self-management courses, and volunteer / peer-led support have a place, they are not remotely adequate or equipped to manage or resolve long-term and / or moderate-severe psychiatric illness, the consequence of which is escalating mental and physical impairment, additional morbidities, complexity, and marginalisation which, eventually, become intractable problems incurring considerable personal, social, and economic costs.

Our members were also keen to point out how prejudices and inequalities in the delivery of healthcare services can also make their health and healthcare experiences worse, impacting on psychological and physical wellbeing. As outlined earlier on in this submission, social model of disability and unconscious bias training would undoubtedly help – but this type of education needs to start early on in people’s careers and lives. Ultimately, it is *people* who design systems so improved understanding is vital if we are to prevent and address wide-ranging barriers to care, including historical perceptions which have resulted in a lack of research, treatment, investment in provision, and accessibility. One key example of this is the continuing failure to include menstrual and gynaecological health conditions in the Quality and Assurance Improvement Framework for Primary Care in Wales (QAIF)<sup>12</sup>.

The QAIF is designed to drive data collection, analysis, and investment in innovation in service delivery for conditions which are considered to have a significant public health burden. Given the numbers affected by menstrual and gynaecological symptoms which, for a considerable number, can indicate underlying disease and become chronic in nature, the absence of related conditions from the QAIF Disease Register<sup>13</sup> seems to suggest that these diseases are considered less important and less worthy of investment than others. This perhaps reflects wider societal perceptions and prejudices. Lack of

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<sup>12</sup> <https://www.bma.org.uk/pay-and-contracts/contracts/gp-contract/welsh-gp-contract-2022-23>

<sup>13</sup> <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Primary-and-Community-Activity/GMS-Contract/qualityassuranceandimprovementframeworkqaifdiseaseregisters-by-localhealthboard-cluster-gppractice>

appreciation for the seriousness of symptoms can result in patients feeling increasingly anxious and traumatised by medical appointments, sometimes making them reluctant to seek help in the future, with potentially catastrophic results.

**Our members told us:**

*'(I am) suffering with anxiety regard(ing) all medical appointments due to the continuous fight and effort on my part to be listened to...Then you come across a new specialist who removes an already instated diagnosis by other experts as he personally thinks you're "too young to have a chronic illness".*

*'(I am) currently being referred elsewhere...adding unnecessary stress and need to attend appointments. (There are) no services offered to deal with chronic pain and the effect of that on mental health despite my own research showing they do exist. (I) have not tried to be referred as I currently don't have the energy to try to push for the referral'.*

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*'All of my conditions coincide with each other and make each other worse so having someone who knows the damage the one can impact (on) the other would help'.*

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*'It's nuts that there is no joined up thinking around different conditions. I have a fibro diagnosis but have always had funny skin - horrible scars, ulcers, twisty clicks poppy joints and I'm autistic so I imagine that I actually have EDS, but I manage it well myself so I don't think there's any point pursuing a further diagnosis. Also when I spoke to the mental health nurse (the third time in my life I've sought mental health support) she would not accept that my body pain was a symptom of my mental health struggles (and caused by autistic burn out) it was so box-ticky'.*

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*'Medical professionals stance on this is appalling. They pretty much never understand that chronic physical health conditions can impact mental health.*

*To the point that it's dangerous to even mention that your physical health is getting you down mentally, because if you do they immediately assume the mental health is the precursor and so therefore your physical symptoms are all manifestations of that, rather than the other way around. And then the "it's all in your head" comments (which are already astronomically high for chronic ill health sufferers) ramp up to even higher levels. So you are left with the best option being to never get any support for your mental health, because that will jeopardise already poor levels of care for your physical health. This is obviously a horrendous position to be putting people in'.*

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*'I am very lucky, and I know I am that I am articulate and outspoken or I would have been dead a long time ago. I am not exaggerating here. Looking back on my life, I realise that I have had pain for most of it and that impacted on my life and mental health. I had endometriosis and was offered a hysterectomy for it. Not only do I know that it would not necessarily have worked anyway, but I now recognise that the pain I was in, mentally and physically was used against me by abusive people in my life. I did not have the energy to fight it because I was so worn down. I had one doctor once listen to me, but I had to see him in secret. I think my doctor now would listen and act, but she is amazing. Shame that she seems to be in the minority'.*

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*"It's ok to not be ok" seems to only apply if you feel a bit down...There is no appropriate care for people with severe and complex mental health conditions, and there doesn't seem to be an understanding of the impact health inequalities have on our mental health. Six weeks of counselling / CBT seems to be the only option for us'.*

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### **3) Impact of additional factors**

#### **3a) The impact of the pandemic on quality of care across chronic conditions**

FTWW wishes to emphasise that the pandemic has added to pre-existing challenges for those living with chronic conditions, shining a light on problems

which were already impacting negatively on patient experiences and outcomes, as well as exacerbating them.

According to many of our members, prior to the pandemic, they were on waiting lists already in excess of guidelines for the various conditions with which they are living, and that these waiting lists have simply grown longer. One factor contributing to this and which preceded the pandemic has already been described within this submission: the expectation that all patients will be best-served by services within their own health board, even if those services are not able to provide optimal care in line with NICE or equivalent clinical guidance. Care closer to home is exactly what people want in an emergency situation, for minor ailments, common health complaints, symptom monitoring and management but, for more complex conditions, where more specialist care is required, it's having a significant knock-on effect on local care systems and waiting lists. Patients describe feeling as though they are in a 'revolving door' of less effective treatments, with limited options to access the more optimum care they need elsewhere. The impact on patients' experiences, outcomes, local waiting times, and the public purse cannot be under-estimated.

According to our members, another associated issue for those on long waiting lists is the lack of information they receive during that time. It's not uncommon for healthcare personnel to move on and / or retire in the intervening period which, for patients with chronic conditions and multi-morbidities, can result in poor / missing communications, repeat testing, and fragmentation of care as diagnoses and treatment plans change. They describe limited support to help manage symptoms and deteriorating health during extended waiting times and what little there is is usually in the form of webpages which not everyone can access. Inevitably, the reliance on an increasingly over-stretched third sector to provide support is problematic in a funding landscape which can result in short-lived programmes and high staff turnover. Meanwhile, patients can find their socio-economic circumstances impacted as they wait for treatment: FTWW members have described losing their jobs due to unmanaged symptoms and, as they become more disabled, their risk of experiencing domestic abuse rises<sup>14</sup>.

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<sup>14</sup> <https://www.womensaid.org.uk/information-support/the-survivors-handbook/the-survivors-handbook-disabled-women/>



Another consequence of the pandemic has been the reprioritisation of care: as outlined in our response to question 2a, across the UK, 'benign' gynaecology was amongst the first specialism to see staff redirected to other areas and theatre time reallocated. Even now, colleagues working in this space tell us that they do not have sufficient theatre capacity to reduce the existing backlog of patients, let alone tackle new referrals. Limited time in theatre also has implications for the future workforce, with gynaecology trainees not able to develop the surgical skills they need, with potentially alarming consequences for patient outcomes.

Also outlined in section 2a is the increasing difficulties patients are having in accessing primary care. For patients with chronic or fluctuating conditions and complex needs, being able to access a GP who knows their history is vitally important, not least to help them manage and understand the implications of new symptoms and treatments, go through test results, deal with long waiting times, and navigate multiple specialisms. However, many FTWW members report finding that primary care has become inaccessible to them, with systems put in place that create obstacles to seeking help and securing appointments which meet their needs and capabilities. They tell us they feel frustrated with public messaging that advises them to 'speak to a GP' when this is so difficult to achieve; similarly, health board and Welsh Government advice that they seek assistance from a local pharmacist has simply seen the problem transferred to a new, less than ideal location. FTWW members have described local pharmacies requiring people to queue up outside the premises, not having a private space or sufficient staff to conduct consultations, not offering the tests required, and ultimately needing to go back to the GP for assurances and / or authority to make changes to treatment regimens.

A further impact of the pandemic on people with chronic conditions and multi-morbidities has been increasing isolation, loneliness, and escalating deterioration of mental wellbeing. There is some evidence to suggest that those with pre-existing and severe mental health conditions have found engaging with services during and since the pandemic more challenging for a

number of reasons<sup>15</sup> but not least because limited personnel and services have been redirected towards dealing with an influx of new referrals, albeit people with 'lower-level' mental health needs. Unable to access either their GP or their usual mental healthcare professional, there are undoubted implications for the physical and mental wellbeing of these patients.

### **Our members tell us:**

*'Covid for me (a disabled woman) meant I had 2 hours a week support stopped. I had no contact with anyone for 2 years. It is only recently, the last few months that any support has started again. I can't help feeling that Covid was a perfect excuse for the services to not actually offer any support.'*

*'The recent support workers are all young girls, age 18 to 22. I have no complaints about them, they are all lovely. They are my only support and help to get out and about as I was given a Housing Association flat after yet another assault in my own home. I do wonder though; Is that really what carers / support (workers) should be doing? Driving assaulted and disabled women around? Is there no other help and support available to women?'*

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*'I have...Long Covid (and) am heading towards dismissal on the grounds of ill health...Why is research into long COVID so slow when the vaccine was so fast? Why are reasonable adjustments actually unreasonable for the person who is ill? Does the government realise how many of us are extremely debilitated after COVID? Why is there no compensation scheme after we all worked so hard in the Pandemic?'*

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*'The change to phone and/or online appointments is helpful in some circumstances, but being able to be seen in person is still important, if not essential in some cases. Therefore in some instances I would say that the pandemic did negatively impact some services. Pain conditions will have worsened as people wait for operations like hip replacements'*

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<sup>15</sup> <https://www.theguardian.com/society/2021/apr/25/mental-health-patients-missed-out-on-care-during-covid>

*'This has been a mixed bag for me. On the negative side I got dropped from two waiting lists accidentally (apparently) because of the extra pressure the NHS has been under. Plus hugely extended wait times for a lot of services. On the positive side it introduced the option for video and phone consultations in a lot of areas that didn't previously have them. However, now we are so far into it, some have regressed to not offer these options any more, leaving disabled people with fewer access options again. And mask wearing, that was great not just for stopping the spread of the pandemic, but for protecting patients with compromised immune systems. Except now, despite the fact we are still in a pandemic, loads of people (and by people I mean medical professionals and admin staff) have just stopped wearing them'.*

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*'It has been awful. And the aftermath of trying to catch up has also been awful. I think it doesn't help that, especially for neurodivergent people, that the information on ballpark timings has not been there. I understand that it is difficult, but it is adding to distress'.*

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*'I found a fantastic team with one GP in particular who was knowledgeable and helpful. I haven't been able to see her since before the pandemic, and during that time my mobility has decreased so much that I cannot walk outside of home...There is no urgency from any NHS healthcare professionals I see to establish a cause or offer robust help and support, let alone recovery pathways. It honestly feels like no one could care less...My health has declined so much and there seems to be no way of improving it. Services were broken before the pandemic, Covid has had a catastrophic impact on them'.*

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### **3b) The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing**

There is a wealth of evidence to show how being disabled and / or living with chronic health conditions incurs additional costs to the person affected and their families. Costs include things like special diets, supplements, therapeutic interventions which aren't necessarily available on the NHS, but which are frequently thought to help with symptom management, like acupuncture,

pilates / yoga, massage, and hydrotherapy to name but a few, as well as mobility aids, taxis, and carers.

As already described in our response to question 2a, it seems that a not inconsiderable number of people living with chronic and complex conditions have incurred debts as a consequence of paying privately for healthcare, with many feeling like they had no other option. These costs are in addition to the increase in basic expenses, like energy, fuel, and food. It's worth pointing out that people with chronic health conditions and impairments may well need to do extra washing, require their central heating on for longer periods, or have to use more electricity than the average (non-disabled) person for essentials like charging up electric wheelchairs, scooters, and other apparatus. However, as the Bevan Foundation's recently published data<sup>16</sup> demonstrates, disabled and chronically ill people are also amongst those most likely to be in poverty and least able to afford the rising cost of living – without the expense of servicing debts on top.

FTWW is also aware of concerns about proposed changes to council tax in Wales being expressed by disabled people and those living with chronic conditions which might see them even more financially disadvantaged. We would urge the Committee to make recommendations to the Minister and officials that disabled and chronically ill people not be amongst the 'losers' mentioned by the Minister for Finance and Local Government, in her update on Local Tax Reform.<sup>17</sup> Those who have spent money on their houses making adaptations such as a downstairs bathroom or additional bedroom / living space for visiting carers, equipment, or office space to allow them to work from home, as this is often the only accessible option open to them, are worried that they may be penalised during any property evaluation and re-banding process, despite being on comparatively low incomes.

Policymakers need to be aware that not all disabled and chronically ill people are unemployed and in receipt of full council tax relief. They may be working part-time and / or in less secure jobs with lower wages because of their health,

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<sup>16</sup> <https://www.bevanfoundation.org/resources/a-snapshot-of-poverty-in-winter-2023/>

<sup>17</sup> <https://record.assembly.wales/Plenary/13340#C499465>, point 174

making it even more important that changes of this nature are fully co-produced with citizens so as not to have unintended consequences for people in already challenging circumstances. As emphasised in the Welsh Government-commissioned ‘Locked Out: liberating disabled people’s lives and rights in Wales beyond COVID-19’ report<sup>18</sup>, it is vital that equality and socio-economic impact assessments are properly and meaningfully undertaken when considering new policy and practice so that decision-makers avoid adding to the stress and hardship that often comes with living with chronic health conditions and multi-morbidities.

### **Our members tell us:**

*‘From knowing what I am like and what other people with chronic conditions are like, I would say that the effect on their mental health in terms of worry is huge with regards to cost of living. This in turn creates or increases anxiety as a mental disorder. The worry can and does exacerbate physical conditions in terms of pain and other symptoms. Those with chronic illnesses may also isolate themselves at home in order to try to save money, but in turn that can increase loneliness’.*

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*‘The impact of rising costs can affect people in multiple ways like loss of home; not being able to afford to keep house warm when living with the said conditions will obviously make conditions worse’.*

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*‘I get the lower rate of PIP for Daily Living and Mobility and what with utility bills nearly doubling, I am having to cut out the foods that are on the expensive end. Avocado is really good for me and helps my joints and I can’t really get them now. I take supplements that help my concentration but they are not cheap. I am surviving, but my quality of life is lessened’.*

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*‘I used to have massage treatments every two weeks which were hugely beneficial – I can now only afford these every 4-6 weeks. The costs of my*

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<sup>18</sup> <https://www.gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19-html#75307>, ‘Accessibility of Public Services’

*supplements have increased. I have been advised to try acupuncture but can't afford to. I was having private mental health therapy every two weeks and can no longer afford it. I would like to try and swim every week (that is one exercise I can do even if I just get into the pool to take pressure off my joints) but I am worried about the costs – it's a very cheap activity compared to gym memberships but getting there isn't always easy. I worry about the cost of electricity as I need it to charge my wheelchair batteries. I have to have regular baths and showers and worry about heating costs even as we go into warmer weather'.*

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### **3c) The extent to which services will have the capacity to meet future demand with an ageing population.**

There is much to be done if Wales is to meet the needs of an ageing population, especially as Wales has a disproportionately higher number of older people than the rest of the UK<sup>19</sup> and is 'the most economically deprived of the UK nations and that this lower income per head has "likely impacts" on health and wellbeing, and demand for NHS services'<sup>20</sup>. Clearly, more needs to be done to address income inequality which, as the OECD notes, is amongst the biggest drivers of health needs in Wales.

In their 2021 Co-operation Agreement<sup>21</sup>, the Welsh Government and Plaid Cymru make clear their 'ambition to tackle poverty and inequality across the country' through the 'devolution of the administration of welfare', making a commitment to exploring 'the necessary infrastructure required to prepare for this administration'. We would ask that any developments in this space better reflect the social model of disability and the right to 'independent living'. It will be interesting to see an evaluation of the Universal Basic Income trial piloted with care-leavers in Wales to understand if and how this might be extended. Certainly, there is evidence to suggest that UBI can give people more financial security, enabling them to pursue education, volunteering, and employment opportunities typically not open to them and also improve wellbeing, reduce

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<sup>19</sup> <https://www.bbc.co.uk/news/uk-wales-35533172>

<sup>20</sup> *ibid*

<sup>21</sup> <https://www.gov.wales/co-operation-agreement-full-policy-programme-html>

stress, and enable people to lead healthier lives<sup>22</sup>. Ultimately, this may have the potential to reduce demand on a health and care service which is creaking under the weight of need.

At the same time, Wales needs to be in a position to recruit and retain health and care professionals, so investment is required to make these sectors attractive, both to young people in Wales and trainees / medics outside of Wales. Evidence suggests that healthcare professionals tend to stay in the area where they're undertaking training<sup>23</sup> so more needs to be done to develop training provision in parts of Wales where there are currently limited opportunities in this regard.

From our understanding, another factor in clinicians' decision-making when it comes to their location is how far clinical settings are set up to succeed: improving patient outcomes as a result of research, participation in clinical trials, innovation, technology, the opportunity to specialise and work as part of multi-disciplinary teams and regional networks of expertise are all drivers for healthcare professionals looking to establish themselves and their practice. However, as it stands in Wales, there are systemic and funding barriers preventing hospitals being centres of excellence able to take patients from across the country.

One example of this issue is outlined in FTWW's report, 'Making the Case for Better Lupus and Rare Autoimmune Disease Provision for Patients in Wales'<sup>24</sup>, which describes a complete absence of Lupus Centres of Excellence in Wales, with no appetite from any of the health boards to take on a fully-funded (by LUPUS UK) a specialist lupus nurse. This is despite the charity's findings which show that 'all of (its) UK-funded Specialist Lupus Nurses are subsequently adopted by their Trusts after the initial five years of funding expires (with) evidence show(ing) that they can recoup their employers this initial outlay and more, as well as play an integral role in improving patient health and well-

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<sup>22</sup> <https://www.jrf.org.uk/report/universal-basic-income-good-idea>

<sup>23</sup> <https://bmcmmededuc.biomedcentral.com/articles/10.1186/s12909-018-1414-9>

<sup>24</sup> <https://www.ftww.org.uk/2021/wp-content/uploads/2021/09/Making-the-Case-for-Better-Lupus-and-Rare-Auto-Immune-Disease-Provision-for-Patients-in-Wales-Final.pdf>

being'. Lack of capacity to develop and fully support the addition of specialist nursing in rheumatology has been cited as a reason.

We very much hope to see new National Clinical Networks and Implementation Groups embedding the third sector and patients in their work plans so that priorities of this nature can be explored and fulfilled – ultimately, it is only through collaboration that we can hope to most effectively address future demand for health and care services.

### **Our members tell us:**

*'I am only 42, but I feel I have already been written off as never being able to have a job, never being able to have a family, never being able to live unsupervised without being labelled an angry aggressive women who must at all cost be controlled. Remember I was the woman who was unofficially caring for an alcoholic for years and called 999 several times. I was assaulted, and I will spend the rest of my life with officially labelled disabilities. There seems to be nothing I can do about this, and there will be millions more like me'.*

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*'I have no hope for the future...my pension does not match my living expenses and I'm just about to go into a nightmarish state of absolute poverty. The situation is terrifying. I must say I have never seen so much covert misogyny in my life as I have in the past few years of trying to get help with declining health. I just want out of this reality as my conditions are already nightmarish to begin with and ageing will only make it all worse'.*

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*'I don't think they (NHS) will have the capacity. There isn't the capacity now to meet need, let alone if the demand increases'.*

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*'Services can't meet demand of chronically ill and disabled people. We are getting older, and our health will continue to decline with a severe lack of social care – I don't have any confidence in this at all'.*

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*'The NHS needs proper investment and co production, not stripping and destroying. Also, much of the change that is needed is to do with training issues so Welsh Government needs to stop using devolution as an excuse to sit on their hands'.*

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#### **4) Prevention and lifestyle**

##### **4a) Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).**

When asked to consider prevention and early intervention, the conversation often turns to the role of Public Health, such as screening. With this in mind, FTWW is 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.

People engage in harmful behaviours such as smoking, excessive alcohol intake, or illicit substance misuse, etc, for any number of reasons and many of those will be complex. Causal factors aren't usually fully considered or addressed when developing and communicating public health interventions which may explain why they continue to be of only limited success. It is vitally important that governments and public health leaders actively engage with citizens to understand their circumstances, what drives them to make unhealthy choices, and work towards addressing those underlying issues if we are to have a healthier, happier population in Wales.

Regardless of the above, however, and as already outlined in this submission, prevention and early intervention is not *\*just\** down to the decisions and behaviours of citizens, despite public messaging and policy statements to the contrary: the NHS also has a responsibility to intervene early on in patients' journeys and enable them to access optimum care which meets their needs. There are evidently gaps in health and care professionals' training that results in patients' voices not being adequately heard, shared decision-making (as per

NICE guidelines) not being a reality<sup>25</sup>, and services inaccessible or exclusionary, all of which causes delayed diagnosis and support.

Having one or more of the protected characteristics increases people's risk of encountering discrimination and disadvantage leading to health inequities. Work is underway in Wales to co-produce a range of equality action plans which aim to address key issues in this regard. The Welsh Government's Disability Taskforce is particularly focused on health and wellbeing, in recognition of the fact that it is social structures (including public services and the delivery of health and care) that play a key role in disabling people with impairments and chronic conditions and that activity needs to be directed towards eliminating the multifarious barriers responsible.

There is a lot to be done to build trust between public services, professionals, and citizens affected by health inequality. Too many describe feeling let down, betrayed, even traumatised by systems and providers to take on board public messaging around their health. Services need to be trauma-informed if they aren't to inadvertently perpetuate ill-health and further disable and disenfranchise people. As already described, this starts with proactively engaging with people, and then ensuring that services are co-designed, accessible, and suitably equipped so that, where possible, further deterioration and increased dependency can be avoided.

### **Our members tell us:**

*'I did try to seek prevention and improve my lifestyle - I called 999 several times, both police and ambulance...I am a 42yr old woman, disabled by abuse and I will be like this for the rest of my life. There are more like me who you will have to deal with, and the number of women who have been given a so called 'mental diagnosis' is ever growing so you will have to deal with them too.*

*'These women do not have a 'mental disorder', they are experiencing trauma and their reaction is perfectly normal...The sooner this is acknowledged the better. You will have a much bigger percentage of an unhealthy population*

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<sup>25</sup> <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>

*seeking and needing and getting support very soon if you continue to misdiagnose people’.*

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*‘We should all do our best to live as healthily as possible but it isn't always possible. There are so many issues involved in terms of access, finance, and the ability of the person to exercise and cook from scratch. Also, several chronic illnesses are not related to factors such as diet etc or doctors do not know what the causes are, for example fibromyalgia, so exercise isn't a prevention’.*

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*‘Prevention measures like regular checkups or reviews on patients and medication. For example, I was never told being a sufferer of psoriasis that I could end up with arthritis and was supposed to be checked every 5 years for signs but was not, or the fact I've been on medication for over 9 months and no one has reviewed the medication or told me of impact of long-term medication use’.*

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*‘Proper investment in housing and other socio-economic factors. Listening to people about what actually ails them instead of guessing’.*

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*‘Anyone who continually calls themselves a "professional" I do not and will NEVER trust...The total system has been set up for parental failure especially if personality clashes or cultures are ignored. Let alone a person who has a "history" ...Services (should be providing) support to help your family as a whole. (Instead, they) disrespect, disregard...Why am I disabled because the British system made me that way’.*

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**4b) Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.**

**Our members tell us:**

*‘There's no doubt that the smoking ban has been a big success but efforts to tackle obesity are a lot more patchy. Fast food is cheap, readily available, and*

*for many with chronic conditions, an unhealthy meal is better than no meal, and they should not be judged harshly for that. Many conditions are actually made worse by exercise, or limit the person's mobility, such as ME/CFS. There's a long way to go to address barriers and also social attitudes'.*

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*'The only advice I am getting from the NHS is to do CBT and exercise. Exercise is potentially dangerous for people with ME and – despite the NICE guidance removing exercise and CBT as treatment methods for ME due to that danger – I keep being asked about exercise (and) the National Exercise Referral Scheme – none of the classes are accessible in terms of activity or times (sick and disabled people do work too)!'.*

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*'The onus is placed entirely upon the patient; eat a perfect diet, exercise often, lose weight, don't smoke, drink, or take drugs. Many patients living in severe pain or with other debilitating symptoms, on long waiting lists, will self-medicate – especially when the NHS is not radical or proactive in helping to prevent or intervene with severe pain or symptoms. If we fail in these activities, we are seen as undeserving of treatment and care'.*

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*'Good lord, can we stop already with having a go at fat smokers and start looking at socio-economic factors. I'd be skinnier if I could get to the pool all the time, if I could get to the gym with a PT who was trained to work with wheelchair users who are hypermobile. I stopped smoking when I temporarily stopped breathing. But...people need something! I am not an over eater and not a smoker yet I am ill. What I am is a product of growing up neurodivergent and poor. Fix that'.*

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### **General Comments and Concluding Remarks:**

We would wish to draw attention to key documents which have the potential to bring about positive change, including:

- Locked out: liberating disabled people’s lives and rights in Wales beyond COVID-19<sup>26</sup>

Published in July 2021, this report originated from discussions at the Welsh Government’s Disability Equality Forum, Chaired by Social Justice Minister, Jane Hutt, MS. It examines the different ways in which disabled people were being negatively affected by the pandemic and beyond. One of its chapters explores health and wellbeing in more depth<sup>27</sup>, and many of the findings can be applied to the experiences of those living with chronic conditions. Recommendations and implementation plans are currently being discussed by the resulting Disability Rights Taskforce. **The Committee may wish to engage with the Disability Rights Taskforce as part of its evidence-gathering.**

- NHS Wales Duty of Quality<sup>28</sup>

FTWW hopes that the Duty will help to support people living with chronic conditions to access the services they need, in the time and place of their choosing. Enabling shared decision-making in this way should constitute a measurable outcome within the NHS in Wales as part of patient-reported experience and outcome measures adopted across all health boards.

FTWW believes that coproduction with service-users / patients should be built into processes to design and evaluate health and care services. This approach means services are more likely to be fit for purpose, meet patient need, and don’t further entrench barriers that many disabled and chronically unwell people experience but are often disempowered from articulating, largely due to inaccessible processes or structures.

Enabling patient voice and demonstrating its being heard underpins value in healthcare but is also a mark of ‘quality’, with providers being more likely to be compliant with the Duty if mechanisms are in place to facilitate and embed those voices. In line with NICE guidance on Shared Decision-Making<sup>29</sup>, this may mean having a Patient Director or equivalent at the highest level of health

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<sup>26</sup> <https://www.gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19>

<sup>27</sup> <https://www.gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19.html#75303>

<sup>28</sup> <https://www.gov.wales/duty-quality-healthcare>

<sup>29</sup> <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>

board activity, who could advocate for patient involvement and co-production throughout organisations.

We are also keen to see this approach embedded within the NHS Wales Executive and its clinical networks so that people with lived experience of the health conditions being considered can convey gaps, barriers, and priorities from the perspective of those using services. Too often, assumptions are made about what patients need and want, which can result in poor experiences, less optimum care, variation, and inequality. People with chronic conditions deserve better, and the new NHS Executive in Wales presents an excellent opportunity to ensure positive change in the way that patients, their representatives, and the third sector are included in health strategy, action, and oversight. **We would like to see the Committee focus on how far people with chronic conditions and their advocates are supported to participate in decision-making, both in health board activity, and at a national level.**

- NHS Wales Duty of Candour<sup>30</sup>

FTWW is hoping that this Duty, alongside pre-existing complaints processes and data collection, provides meaningful opportunities for the NHS to become a culture which genuinely learns from its interactions with patients (both with and without chronic conditions). In this way, preventative measures can be co-produced, avoiding repeated mistakes and concerns, and best practice shared as a matter of course both locally and across Wales. Ongoing monitoring and evaluation will be an important part of making sure that the Duty of Candour is having a positive impact, both in terms of redress for those patients whose experiences have triggered it but also for those who come afterwards. **The Committee may wish to examine ways in which organisations' reporting on the Duty of Candour and other complaints or concerns data can be used as learning to improve the experiences of those living with chronic conditions across Wales.**

- Women's Health Wales Coalition Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth<sup>31</sup>

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<sup>30</sup> <https://www.gov.wales/nhs-duty-candour>

<sup>31</sup> <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf>

FTWW currently co-Chairs the Women's Health Wales Coalition, which has brought together health-focused groups and charities, equality networks and organisations, academics, clinicians, and patients to provide evidence of need to the Welsh Government and NHS in Wales. The result has been a ministerial commitment to a 10-year NHS Wales 'Women's Health Plan' which we now want to see coproduced with public, patients, and the third sector so that it properly considers lived experiences of, amongst other issues, chronic health conditions.

**We would ask that the Committee continues to prioritise women's health in its agenda for this term, so that it can scrutinise how far the Plan is being developed coproductively, that its implementation takes place in a timely fashion, and that patient / third sector insights are embedded into that process.**

**We would also ask that Committee members continue to highlight the disproportionate impact of chronic illness on women and people assigned female at birth so that *all* services, policy and practice, are designed to better accommodate our needs, prevent deterioration, and avoid further inequity.**

#### **Concluding comments from our members:**

*'My endometriosis nurse is an angel (but) one endometriosis nurse per health board is (not) adequate or sustainable – we need more, as well as the recommendations from the 2018 (Endometriosis) Task and Finish Group report to be actually implemented. These recommendations are five years old. Where is the urgency and recognition of what this disease does to people?'*

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*'As a woman living with ME/CFS, whose life has been turned upside down by the condition, I would like to express the difficulties I have faced with the illness itself and also via the NHS support. I have not worked for six years due to my mental health initially, but it then became clear to me and my husband that I was experiencing other symptoms. It took years of blood tests and back and forth to the GP (plus the pandemic slowed it down even more) to get to a position where the GP would consider referring me to receive a diagnosis of ME/CFS. It was my husband advocating for me that got the referral, if left to*

*the GP I would still be without answers as they were sure there was nothing further wrong with me.*

*'Since the beginning of 2023, my ME symptoms have worsened and I feel forgotten and undeserving of care from the NHS. I spend up to 20 hours a day in bed, barely leave the house and if I do, rarely leave the street I live on. I struggle to wash myself and rely on my husband to provide groceries and do the laundry, and often to bring me meals on a tray in bed. The GP has no advice or support to pass on and it is very demoralising. More funding and research is required desperately into ME/CFS as many people like me are existing, not living, forced into their beds and isolation for years on end. I am 36 years old but I have neighbours in their 80s with better health and social lives than me.'*

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**FTWW would like to thank the Committee for focusing on 'Support for People Living with Chronic Conditions' during this term.**

**FTWW supports women and people assigned female at birth who are disabled and / or living with chronic and recurrent health conditions of various types. We would be pleased to assist the Committee by facilitating focus group(s) with our members so that the Committee can hear, first-hand, about what is and isn't working in Wales with regards to the support for those affected.**

**Please contact us on [info@ftww.org.uk](mailto:info@ftww.org.uk) for further information.**