

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gynllun Llywodraeth Cymru i drawsnewid a moderneiddio gofal a gynlluniwyd a lleihau rhestrau aros](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [Welsh Government's plan for transforming and modernising planned care and reducing waiting lists](#)

PCWL 26

Ymateb gan: | Response from: Fair Treatment for the Women of Wales





Senedd Health and Social Care Committee Inquiry:

The Welsh Government's plan for transforming and modernising planned care and reducing waiting lists

**Name of organisation: FTWW: Fair Treatment for the Women of
Wales**

1. FTWW is the only patient-led women's health equality charity in Wales, supporting and advocating for women and people assigned female at birth who are disabled and / or living with long-term health conditions in Wales. We campaign for better women's health services and equitable access to them, particularly as many of the health issues which predominantly affect females have suffered historical lack of investment and prioritisation in Wales and beyond.
2. **The Committee asks whether the plan will be sufficient to address the backlogs in routine care that have built up during the pandemic and reduce long waits.**
3. We note that the first of the Welsh Government's Five Goals for Planned Care is 'Effective referral to the most appropriate setting'. However, at the same time, there continues to be a strategic commitment to 'care closer to home'. This creates a potential contradiction which the Welsh Government will need to address head-on and communicate to both patients and health boards. Whilst FTWW's members have long

expressed a willingness to travel for more specialised services, other people may have differing views and / or issues which make travelling more difficult – the Welsh Government and health boards will need to ensure there are mechanisms to engage effectively with individuals affected and, where necessary, provide them with the necessary support to access services situated farther afield.

4. It should be said that FTWW is fully supportive of any move towards routinely enabling patients to cross health board boundaries to access ‘most appropriate’ care, which must include specialist services unavailable in their locality, the historical prevention of which has created a significant postcode lottery in Wales. With this in mind, we also note that there is no reference to tertiary care in the section exploring ‘integration’, an omission which needs rectifying.
5. When describing ‘care closer to home’, we would argue that there is a need for more detail regarding what those services might be and for genuine engagement with public / patients to establish their views about the services they would expect to be delivered within the community. For our members, this would constitute services like pelvic physiotherapy and low-level mental health support targeted at those living with chronic health conditions and pain.
6. As already mentioned, we are pleased to see a reference to ‘regional (diagnostic) centres’ but would like to emphasise that even the provision of (presumably low complexity) high volume services will, in some instances, require upskilling of personnel if we are to avoid missed diagnoses and repeated referrals into services.
7. In FTWW’s recent submission to Health Education and Improvement Wales’s Education and Training Plan 2023-24 consultation, we mentioned the need to improve diagnostic capabilities in gynaecological ultrasound, as well as more investment in minimal access training for gynaecologists across Wales. Given that gynaecology is listed as one of the specialties with the greatest number of people waiting, this will be essential if we are to ensure patient need can be adequately addressed both locally and in regional centres.
8. **The Committee asks whether the plan strikes the right balance between tackling the current backlog, and building a more resilient and sustainable health and social care system for the long term?**
9. Regional working and centres of excellence are concepts for which FTWW has called repeatedly as a way of better treating a number of health conditions with which our members are living. However, we wonder how this move fits with the Welsh Government’s previous decision not to offer multi-disciplinary centres / one-stop shops for long COVID and similar conditions like ME and, also, (rare) auto-immune conditions

like lupus. We hope that this Plan means that there will be scope for further discussion with patients affected to ensure that these populations can similarly anticipate a move towards multi-disciplinary centres of excellence.

10. We would also ask that the Welsh Government explicitly acknowledge that, in some instances, travel outside of Wales will be required and that it will investigate ways to support those people with limited means / capacity with their additional travel needs.
11. When it comes to ensuring resilient and sustainable services, co-production is rightly mentioned as being key. However, this firstly requires agreement on what it is / what it entails (it isn't just 'engagement' or 'consultation'). We welcome use of terminology like 'involvement' and 'collaboration' but this needs to come from a place of equity of esteem and value, particularly as the Plan describes co-production as a means to deliver 'value-based care'.
12. For patients to be involved and collaborators in health service design and evaluation, they need to be properly supported throughout their participation and beyond, and this often requires time, commitment, and careful facilitation – all of which FTWW has been pleased to offer the Welsh Government and health boards over the last few years. However, we still encounter barriers to participation on occasions, with service providers not fully cognisant of what co-production involves or its benefits. Additionally, there remains a lack of resourcing for this kind of activity which poses considerable challenges to its sustainability and further expansion. We would urge the Welsh Government to address this funding gap as a priority if it is serious in its commitment to embedding co-production in strategic planning, decision-making, and service design.
13. The Plan mentions a few instances where a co-productive approach will be taken, including the development of patient pathways. We would urge the Welsh Government to expand this to include the development of PROMS and PREMS, cited throughout the Plan as being vital instruments in assessing service effectiveness. This is important to ensure that the right questions are being asked and in the most user-friendly way. Similarly, with regards to 'one-stop shops', we would urge that robust engagement with patients takes place so that we can be sure they fully accommodate patient needs.
14. **The Committee asks whether the plan includes sufficient focus on:**
 - **Ensuring that people who have health needs come forward;**
 - **Supporting people who are waiting a long time for treatment, managing their expectations, and preparing them for receiving the care for which they are waiting, including supported self-management;**

- **Meeting the needs of those with the greatest clinical needs, and those who have been waiting a long time;**
- **Improving patient outcomes and their experience of NHS services**

15. We are pleased to see that the vital role of the third sector in supporting and improving the wellbeing of citizens and patients is referenced and endorsed throughout the Plan. In particular, we note the Welsh Government's commitment to a 'national framework for social prescribing to embed access to prevention services and wellbeing activities into our pathways', based on the acknowledgement that the third sector is well-placed to improve cost-efficiencies by 'reducing follow-ups and presentations'.

16. As an organisation supporting a growing number of people in Wales living with long-term and recurrent health issues, helping them to better 'self-manage' their condition(s) and navigate often complex pathways, we welcome the Welsh Government's endorsement of this kind of activity. We have spent several years creating a safe, peer-led space for our members and building both trust and resources so that they are better equipped to manage their own health and advocate for themselves and others. However, a move towards formally integrating a third sector offer into the country's health services also creates the very real danger of over-burdening organisations / groups already groaning under the weight of increasing pandemic-related demand, to the point where they can no longer support those in need of their services. This is an organisational risk to third-sector providers and the NHS but, even more importantly, it runs the risk of leaving clients / patients without a service on which they may have come to rely.

17. Alongside formalising referral pathways into community activities / support, therefore, the Welsh Government must concurrently address the huge funding and capacity gap being experienced by the third sector. We would urge that funding application processes are co-produced to make them accessible to smaller / grassroots providers.

18. The Plan also mentions 'helping people to manage their conditions without surgery' which we would suggest is a laudable aim if not always possible, not least due to lack of investment in research for some conditions, i.e., endometriosis. In fact, for many 'benign' gynaecological conditions, the 'best' offer we currently have is major surgery, such as hysterectomy and oophorectomy - but this is often because no non-surgical treatment or cure has been identified due to a lack of research prioritisation and investment. Certainly, as an adjunct to surgery and / or current medical 'management' of symptoms, we would urge much more emphasis on pelvic physiotherapy, something which we see as being an essential component of 'care closer to home'.

19. We would also like to draw the Committee's attention to the Plan's aim to address 'widening health inequalities' through Public Health Wales campaigns and activities to 'promote' and 'encourage' healthier lifestyles. Unless activity is directed towards engagement, including via grassroots advocacy organisations, endeavours like this will only have partial success because they don't identify or address causation. 'Specific signposting to local support services to help people to achieve and maintain a healthy weight, be more physically active and cease smoking' is referenced as a core part of 'Communications and engagement' but naively fails to include any sense of engaging with people to establish their reasons for not maintaining a healthy lifestyle or attempting to resolve the factors underpinning health inequalities / 'unhealthy' lives.
- 20. The Committee asks whether the plan provides sufficient leadership and national direction to drive collective effort, collaboration and innovation-sharing at local, regional and national levels across the entire health and social care system (including mental health, primary care and community care)?**
21. We are concerned that there is no detailed reference to a NHS Executive in this Plan, not least what we see as the ideal option: an independent entity with sufficient powers to address the most intractable issues currently preventing regional collaboration, making consistent co-production of services a reality, overseeing implementation and performance, and ensuring accountability. We believe that many of the very laudable aims of this Plan will be difficult to achieve without something of this nature in place.
22. We note that one of the key purposes of this Plan is to eliminate the prospect of long waiters at all stages of the pathway – this needs to explicitly reference tertiary / specialist care which may not be available 'close to home' or even in Wales. It is this part of the pathway that has previously proved to be the most problematic in terms of equitable access. The Plan posits, 'regional waiting lists (and) the transfer of patient care across health board boundaries' as the solution, which FTWW would absolutely endorse. However, this approach will require considerable oversight and a much more hands-on approach to health board collaboration.
23. The Welsh Government will need to listen to clinicians, patients, and managers when barriers to collaboration are articulated – not least the block-funding arrangements in Wales which do not always work in the best interests of patients with complex conditions. We believe that the Welsh Health Specialised Services Committee (WHSSC) may be well-placed to address some of these issues but would suggest that its remit be expanded and its deliberations made more transparent, with wider engagement (including with patient groups) a core part of its activity and decision-making.

24. With regards to the Committee's focus on the 'entire health and social care system, including mental health', we do have some concerns regarding the Welsh Government's intention to, '(where appropriate) de-medicalise our approach to mental health services' and wonder if this terminology and approach would be deemed acceptable for 'physical health services'?
25. We believe that there is a vital distinction to be made between mental 'wellbeing' and mental health / mental illness, where mental wellbeing can likely be supported via a non-medical approach, as opposed to mental (ill) health. It is worth emphasising that, in many instances, Wales still doesn't adequately support or treat those with serious mental illness or routinely allow access to tertiary / specialist services where they are not available in the locality, including serious peri-natal mental health issues, eating disorders, or obsessive-compulsive disorder. Nor does the system in Wales routinely ensure that workable shared-care agreements are in place for those forced to pay privately for a diagnosis of autism / ADHD (most likely to be women / people assigned female at birth).
26. Whilst we believe that a move towards regional centres of excellence for various physical health conditions is a positive development, we are concerned that there is no suggestion that this same approach will be applied to those mental health conditions which require a similarly specialised and multi-disciplinary approach. As such, we would urge caution regarding any possible further dilution of mental health services as this may well end up adding to the existing backlog of patients needing to access care.
- 27. The Committee asks whether the plan provides sufficient clarity about who is responsible for driving transformation, especially in the development of new and/or regional treatment and diagnostic services and modernising planned care services?**
28. As mentioned in our response to the previous question, we perceive there to be a lack of clarity in the Plan regarding who has ultimate responsibility for ensuring the development of regional centres / hubs. As patients, we are all too aware that, historically, advice from the Welsh Government to the health boards that 'geographical boundaries should not be barriers to care' has not, for the most part, led to any discernible change. However, we also appreciate how and why the current operational and funding system in Wales creates these barriers. Systemic issues will need to be addressed by an (ideally independent) Executive Team if we are to make Goal 4, 'Giving individuals more choice and control over their care' a reality.
29. The Welsh Government needs to appreciate that genuine commitment to shared decision-making of this nature will require enabling of equitable access to tertiary and specialist services, even if situated out of area (and a reporting system in place for

patients for whom this isn't facilitated) and that this will inevitably lead to increased demand. For this to be manageable on the part of providers, dedicated funding will be necessary so, as mentioned already, it may be that the WHSSC is involved in discussions of this nature. We would strongly urge that a co-productive approach to the WHSSC's decision-making be facilitated, with patient advocacy organisations like our own enabled to have dialogue with the Committee.

30. The Committee asks if the targets and timescales in the plan sufficiently detailed, measurable, realistic and achievable?

31. Whilst the Plan does mention some general (and aspirational) timescales, part of its implementation needs to be making a more detailed workplan publicly available so that patients and healthcare professionals have clear expectations and can hold providers to account should these targets and timescales not be met – this should be seen as a key part of any constructive dialogue.

32. Goal 5 is to, 'Measure what's important, transforming care to better meet the clinical need of the patient'. FTWW commends the Welsh Government's refreshed commitment to patient-centred care and references to co-production throughout the Plan. However, as already mentioned, this requires PROMS and PREMS themselves to be co-produced, consistently collected, and scrutinised alongside more traditional (largely quantitative) performance measures. Unless there are personnel in a NHS Executive team charged with ensuring these measures are universally applied, studied, and used meaningfully / to drive improvement, there will continue to be variation and inequality in service provision.

33. The Committee asks if it is sufficiently clear which specialties will be prioritised / included in the targets?

34. The Plan mentions 7 specialties which have the greatest number of people waiting and which will, presumably be prioritised for attention, although that is not made explicit. As an organisation focused on female health, we are all too aware of the impact the pandemic has had on gynaecology services, although it is important to appreciate that it has merely exacerbated pre-existing issues and gender-based inequalities in health. We are aware that work to improve planned gynaecology is already underway.

35. Crucially, gender bias hasn't just affected those conditions typically associated with female health – as FTWW's work as part of the #WomensHealthWales Coalition has demonstrated, there are a significant number of specialties where women and people assigned female at birth make up the majority of those affected but whose needs are not reflected in service provision and investment: this needs to be urgently addressed if

we are not to perpetuate existing health inequalities. As the Welsh Government looks to direct action towards the 'ten highest demand conditions', it is important to be mindful of the role historical and unconscious biases may have played, and still be playing, in data collection.

36. The Plan states early on that its intention is to, 'Eliminate the number of people waiting longer than two years in most specialties by March 2023'. The Welsh Government needs to be more explicit in its references to 'most specialties' – which ones does it anticipate not being part of this group? We note that openness and transparency are mentioned at various points within the document so this is a significant omission – reasoning should also be given.

37. The Committee asks if we anticipate any variation across health boards in the achievement of the targets by specialty?

38. The Plan describes 'work(ing) with health boards to prioritise diagnostics and identify gaps in demand and capacity at a local and national level'. To get a complete picture, we would advise also reaching out to patient advocacy organisations like our own who have pan-Wales membership and who can help to identify need and capacity issues from the patient perspective.

39. It can be problematic accurately assessing demand if neither clinician or patient are aware of the benefits or existence of a service (as we have found with both pelvic physiotherapy and specialist menopause provision). Without that awareness, a request to access the service won't be made by either party, resulting in an inadequate assessment of need. It is issues like this that can result in variation across health boards in the achievement of targets, so there needs to be a body charged with issuing clear expectations, guidance, and oversight of activity (including communication between health care professionals and the patient community).

40. The Plan goes on to state that, 'Further analysis of the waiting list needs to be undertaken to ensure we really understand variations in access not only from where a person lives but also by their relevant characteristics...' We were surprised not to see sex and gender referenced here, particularly in the context of UK-wide women's health strategies / plans under development precisely to address these historical and enduring disparities in care.

41. Equally, we would urge considerable attention be paid to disability and neurodivergence which see those people affected at particular risk of encountering barriers to appropriate, timely, and effective healthcare. All health boards and personnel should receive training, ideally designed and delivered by those with protected characteristics,

on how best to engage, support, and tailor their offer to individuals / communities affected, thereby reducing the possibility of unnecessary variation and inequality in service provision and access.

42. The Committee asks if there is sufficient revenue and capital funding in place to deliver the plan, including investing in and expanding infrastructure and estates where needed to ensure that service capacity meets demand?

43. The Plan states that, 'We expect health boards to plan services regionally...for specialised services'. Whilst we absolutely agree with this aim, it is not enough to issue an 'expectation' unless there is high-level focus on addressing the barriers and facilitators to making it happen in reality and a designated body charged with ensuring that 'expectations' are met.

44. Clearly, there will need to be funding directed towards both facilities, equipment, and training for personnel in regional 'centres of excellence' if they are to be truly of the highest quality. By ensuring this level of investment, it is possible that Wales could provide services both to domestic patients and those farther afield.

45. In terms of infrastructure, as mentioned, we would see the WHSSC as being a mechanism by which pan-Wales access to specialist services might be facilitated but its remit and functionality would likely need revisiting.

46. The Committee asks if the plan is sufficiently clear on how additional funding for the transformation of planned care should be used to greatest effect, and how its use and impact will be tracked and reported on?

47. The Plan describes the monies allocated to NHS organisations to support planned care recovery plans, but we regret that there is no reference to any funding for the third sector organisations supporting this work, despite the sector being mentioned throughout as an essential partner in both the design and delivery of care.

48. The successful attainment of the five goals mentioned at the start of the Plan very much relies on organisations who can provide direct channels of communication to patients, and facilitate and support their involvement, ensuring a co-productive (and therefore efficient and effective) approach to the design and delivery of healthcare in Wales. This is something the Welsh Government acknowledges will improve patient experiences and outcomes and provide considerable long-term efficiency savings if done properly. We cannot emphasise enough how this kind of activity needs adequate, sustainable, and accessible funding.

49. **The Committee asks if the plan adequately addresses health and social care workforce pressures, including retention, recruitment, and supporting staff to work flexibly, develop their skills and recover from the trauma of the pandemic?**
50. We don't feel that these issues are addressed in any great detail in the Plan as it stands, although we note the reference to Allied Health Professionals (AHPs) and the need for improved access to them in the community, 'without the need to be referred by another health professional'. This streamlined approach would reduce the number of appointments required whilst also empowering patients to take charge of this aspect of their personal healthcare journeys.
51. We would like to reiterate the need for more pelvic physiotherapists across Wales and also alert the Committee to the fact that, as far as we are aware, unlike any other type of physiotherapy service, a referral from either the GP or consultant is required to access these AHPs. Given the prevalence of both pelvic pain conditions, and continence issues, this is both a gap and an anomaly which needs addressing.
52. In terms of recruitment or re-training, we would urge the Welsh Government to explore funded training places and bursaries in exchange for a period of commitment to service-provision in the locality. In addition, the referral requirement for these patients (most commonly women / people assigned female at birth) needs to be reconsidered as it seems a stark example of gender health inequality.
53. **The Committee asks if there is sufficient clarity about how digital tools and data will be developed and used to drive service delivery and more efficient management of waiting times?**
54. With the Plan's stated aim of moving towards a more effective combination of care closer to home and centralised specialist care, we would like to see further exploration of both wearables and digital / remote communications as ways to improve collaboration between specialist and local teams, and the individual patient themselves. This would enable those who have accessed a specialist intervention outside of their locality to be better supported closer to home whilst waiting and afterwards.
55. We note the Welsh Government's comment that 'Strengthening telephone and e-advice services' has proved beneficial for a significant number of patients – but we would also advise that this move has, at the same time, excluded others with particular needs and / or impairments. The Welsh Government and health boards must ensure reasonable adjustments are readily made for those who require them and that inequalities are not exacerbated in the rush to progress remote and digital healthcare.

56. The prospect of unwittingly causing and / or perpetuating inequality is of great concern to FTWW. The Plan states its aim of 'accelerating the embedding of virtual approaches so that 35% of new appointments are delivered virtually', a seemingly arbitrary (and high) target which poses a very real risk of delaying diagnosis and referrals, not least because physical / in-person examinations can play a hugely significant part in expediting access to appropriate care. We are very concerned that a move towards over one third of new appointments being carried out virtually may end up having the opposite effect to that intended by the Welsh Government.
57. The Plan goes on to suggest that provisions for the digitally excluded will be resolved by, 'setting up virtual centres in rural communities'. It is important to remember that it is not just those in rural locations who are digitally excluded – there are many different reasons for not wishing / being able to access or benefit from virtual health appointments which need to be properly explored and ameliorated through a variety of means. We would suggest that there needs to be much more engagement with citizen / patient advocates from a range of sectors to explore causation and solutions.
58. Finally, the Welsh Government acknowledges that the success of this Plan will be underpinned by accurate data, something with which we would wholeheartedly concur. In light of this, we envisage the need for coding to be revisited in secondary care so that diagnoses and modes of intervention / treatment are more accurately recorded. This would allow more accurate assessment of what interventions are taking place and their effectiveness, as well as better tracking of individual patient trajectories. In addition, we would like to see menstrual / gynaecological conditions added to the Quality Assurance and Improvement Framework (QAIF) in Primary Care as this is a key mechanism for collecting data on prevalence and impact, as well as driving improvements in care.