Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth

This response was submitted to the Health and Social Care Committee consultation on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

WT 14
Ymateb gan: | Response from: Triniaeth Deg I Ferched Cymru | Fair Treatment for the Women of Wales

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Senedd Health and Social Care Committee Inquiry:

Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

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 disabled women, people assigned female at birth, and those living with long-term health conditions. 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 pandemic has undoubtedly had a hugely significant and detrimental impact on waiting lists for 'non-urgent' care. However, it has also shone a light on pre-existing problems in Wales, which include:

- a harmful preoccupation by service providers with 'care closer to home' under any and all circumstances
- a system which denies patients choice and often prevents them accessing care 'out of area', even if it is more specialised and can offer better outcomes
- an ongoing failure to take seriously and prioritise women's health needs.

3. All of the above has resulted in thousands of women experiencing long diagnostic delays, postcode lotteries and geographical barriers to optimum care, poorer health outcomes, and associated inability to remain in education or work with significant socio-economic consequences and longer-term disability. There is also considerable impact on local care-providers, with patients experiencing a revolving door of waiting for less specialised care which can only provide short-term or inadequate relief of symptoms, adding to ever-increasing local waiting lists.

4. Evidence shows that 'benign gynaecology' has been the specialism suffering the greatest increase in waiting times (https://www.msn.com/en-gb/news/uknews/women-worst-hit-by-nhs-waiting-lists-backlog/ar-AALJXFr?pfr=1) since the pandemic began, largely because of the assumption that many 'women's health conditions' do not require urgent attention and a subsequent de-prioritisation of hospital-based services for these patients during this time.

5. There are numerous sources, both anecdotal and by way of formal research, which attribute this situation to historical prejudices and stereotypes, where women's pain is underplayed and their symptoms dismissed as being a result of the 'female psyche', or perceived tendency to be more depressed, anxious, and 'hysterical'. Ironically, our members tell us that despite their physical health issues often being misattributed to their mental health, they have rarely, if ever, been referred to mental health services, despite some feeling that this kind of support may well help them to cope with the effects of chronic and acute pain episodes.

6. Health service rationing during the pandemic has seen those with 'benign' health conditions significantly impacted by postponed and cancelled appointments, and lack of interim symptom management. Our members point out that the term 'benign' is both erroneous in the truest sense of the word, and underplays the extent of their suffering, as many of the conditions with which they are living can have harmful consequences for both physical and mental health. In our online community and the focus groups we have hosted for the Committee, we have heard from patients losing their organs to diseases like endometriosis and lupus, and we have heard from people who have made repeated suicide attempts as they are no longer able to manage their chronic pain or mental distress.

7. Accessing benign gynaecology, especially specialist care for conditions like endometriosis and pre-menstrual dysphoric disorder (PMDD), was challenging before the pandemic but has now been rendered almost impossible for many, with significant numbers of patients waiting several years for expert treatment. For endometriosis, a condition with a similar prevalence to diabetes or asthma, there is currently only one fully accredited specialist centre in Wales, in Cardiff. Limited theatre capacity and

historical block-funding arrangements mean that, even though they meet the NICE criteria for referral, patients from outside that health board can now expect to wait up to 7.5 years for multi-disciplinary surgery, even assuming the referral is accepted. PMDD patients ideally require a joined-up approach to care from gynaecology and mental health services. This was largely inconceivable before the pandemic but is now almost impossible to facilitate as services grind to a halt.

8. Similarly, with 80-90% of those people living with autoimmune conditions and connective tissue disorders being female, the impact of extended waiting times for rheumatology services has been disproportionately felt by women, something that was already hugely problematic before Covid-19 measures saw ‘non-urgent’ care largely cancelled. For Lupus patients and Ehlers Danlos Syndrome patients, there are no centres of excellence in Wales, which means that their care is fragmented and insufficiently specialised, often resulting in physical deterioration and the need for repeated, ineffective appointments locally, adding to waiting times for those who might benefit from more routine, local care. This is an issue that was reflected in a number of responses to Welsh Government’s recent Arthritis and Long-term Musculoskeletal Conditions consultation (https://gov.wales/arthritis-and-long-term-musculoskeletal-conditions-adults) and has merely been compounded – not caused – by the pandemic.

9. We are also concerned at the numbers of women and girls with long-standing mental health conditions for whom specialist services were unavailable preceding the pandemic but who are now finding themselves with even less support, largely as a result of the unprecedented pressures on local services. It seems that those with severe and intractable mental illness, such as self-harm, eating disorders, obsessive compulsive disorder, and complex post-traumatic stress disorder, the majority of whom are female and who would, ordinarily, require the most intensive psychological therapies and regular interventions, have been the ones most likely to find care plans halted and services withdrawn. This may well be due to limited local resources being diverted to deal with an influx of new patients impacted by Covid-related issues.

10. Patients with serious psychiatric illness now find themselves on ever-increasing waiting lists, which can partly be attributed to the systemic reluctance in Wales to refer ‘out of area’ for specialist (possibly in-patient) care. Predictably, this is seeing a marked deterioration in patients’ mental wellbeing, potentially making their health conditions more difficult to manage or resolve in the future.

11. Another cohort at increased risk of this is neurodivergent females, i.e., those awaiting a diagnosis of autism and / or attention deficit disorder (ADD). Due to historical gender bias which centres male symptomatology, females can often find themselves dismissed as ‘atypical’, resulting in many years’ delay for diagnosis and appropriate support. As a

consequence, this population will also be on the aforementioned waiting lists for mental health services which may or may not be the correct pathway for them.

12. All of the above information is based on our ongoing conversations with our online community forum. As part of our response to this consultation, we have additionally sought our beneficiaries' thoughts via two focus groups, using the following questions as prompts for discussion:
    i) What help have you received from the NHS to help you manage your condition whilst you await treatment?
    ii) What type of support have you received, either from the NHS or third sector?
    iii) Have you accessed the GP or A&E whilst waiting for treatment?
    iv) How easy has it been to access information on how to manage your condition?
    v) What communication have you received from your hospital or clinician?
    vi) Have you considered or had to use private healthcare?
    vii) What are your concerns, and how do you think your care could be improved?

13. For the most part, our respondents told us that they had received little to no support from the NHS during this time. In fact, lack of communication, repeatedly cancelled appointments, including tests and medicine management, caused a decline in people's physical and mental health, making it more difficult to self-manage symptoms whilst awaiting treatment.

14. Some respondents, who were reliant on pain medication to manage the impact of their health condition(s), found prescriptions weren't filled as a result of cancelled reviews, even if their consultant had written to their GP recommending their continuation. The requirement to self-isolate before interventions which were then cancelled (often on the day) also impacted on people's ability to work and their financial security. Our respondents were particularly concerned about their employment status, as repeated sickness absences can result in disciplinary action and eventual job losses.

15. Many members described having to repeatedly call consultants' secretaries for information, with written letters and test results going missing; others discovered that they had been removed from waiting lists (or weren't put on them in the first place) leaving them confused and 'in despair'. Several respondents described how, had they not had sufficient mental capacity, skills, or family support to advocate for themselves, they would have been 'lost and abandoned', with their health in an even more precarious state. A few members told us that they had been forced to submit formal complaints against the NHS / their health boards, and one described seeking legal advice for medical negligence. Interestingly, none of these respondents 'wanted' to seek such redress but felt they had no option as, they felt, care and communication had been inexcusably poor.

16. A significant number described being forced to pay for private healthcare, borrowing money from friends and family, taking out personal loans, and applying for credit cards. Given that many of our beneficiaries are disabled, with a concomitant risk of deprivation and poverty, this is a significant concern: debts of this nature may not be manageable for the individuals affected in the future, particularly if they lose their jobs due to prolonged and repeated sickness absence.

17. Almost all respondents pointed out that their problems accessing healthcare in Wales pre-existed the pandemic and that related measures had only exacerbated them. Many of them cited difficulties in having referrals to the limited number of specialists accepted, with their GPs expressing similar frustrations, particularly if those specialists were not within the patients’ health board or in England. More than one of our beneficiaries spoke of attempting or feeling suicidal because of escalating ill health and feelings of hopelessness at not being heard or supported adequately by the NHS in Wales. Many of them declared that their only source of support and information during the pandemic had been from organisations like FTWW.

18. It is important for the Committee to be aware that many third sector organisations – FTWW included – who are providing such essential services for citizens, do not receive any funding from the Welsh Government, NHS Wales, or individual health boards. Organisations like FTWW are alleviating a significant burden on the NHS by signposting patients to appropriate services and care, assisting them to navigate referral pathways, better self-manage their health and wellbeing, and feel more equipped to cope with the isolation that comes with being seriously unwell for extended periods of time, not least during the pandemic. However, we are often reliant on the good will of volunteers and short-term, small-scale grant-funding from external providers to continue to provide these services. This is not sustainable and must be addressed as a matter of urgency.