Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar dyfodol ymarfer cyffredinol yng Nghymru

This response was submitted to the Health and Social Care Committee consultation on the future of general practice in Wales

GP61: Ymateb gan: Triniaeth Deg i Fenywod Cymru| Response from: Fair Treatment for the Women of Wales (FTWW)

FTWW

Response to Senedd Health and Social Care Committee Inquiry into the Future of General Practice in Wales

Intro to FTWW

FTWW: Fair Treatment for the Women of Wales is a patient-led charity and disabled people's organisation focused on highlighting and tackling health inequalities experienced by women and people registered female at birth who are disabled and / or living with long-term health issues in Wales.

Overview

General practice in Wales remains the setting in which most patients seek initial information, support, and help with symptoms, and is often considered the 'gatekeeper' to accessing secondary care.

As patients' first port of call, it is imperative that the offer is both broad enough to cover the diverse range of issues with which patients present, and specialised enough to identify potential causation of symptoms and signpost accordingly. Squaring this circle is undoubtedly a challenge and one about which FTWW members often express concern, the majority of whom are living with long-term conditions typically considered 'women's health', such as heavy and / or painful menstrual bleeding, fibroids, endometriosis, adenomyosis, premenstrual dysphoric disorder (PMDD), or polycystic ovary syndrome (PCOS), or with conditions which predominate in women and which might be considered 'rare' but are increasingly described as 'rarely diagnosed' instead, such as lupus, Sjogren's Syndrome, ME, or Ehlers Danlos Syndrome (EDS).

The latter circumstance can arise because symptoms are wide-ranging and non-specific, or because of a lack of investment in research, the reliance on diagnostic models which fail to recognise female presentations (heart attack, asthma, autism spectrum disorder), or because of a societal tendency not to 'take seriously' women's reporting of symptoms. These issues have been identified and incorporated into the

recently published NHS Wales 10-year Women's Health Plan[1]; however, there is much that needs to be done in general practice to improve women's experiences now and into the future.

FTWW members have expressed concern about the implications of previous iterations of the GMS contract for GPs, whose Quality Assurance and Improvement Framework[2] has actively driven data collection, GP learning, and incentivised the development of high quality services for certain health conditions, known as 'disease areas' set out in the contract. Despite the population numbers affected (51%), 'female health-specific' conditions, such as heavy menstrual bleeding, endometriosis, or menopause have never been included in the disease registers, resulting in a long-standing lack of focus on these issues as priority areas for general practice.

As disease registers were typically established on the back of public health impact, patients affected can only assume that they have not been included either *because* they only affect half the populace, or because they are not considered sufficiently important or 'serious'. However, there is a growing body of evidence to show that these conditions incur both significant costs to the UK economy and can have a hugely detrimental impact on individual women's lives and wellbeing.

In its 2022 and 2024 reports, 'Left for Too Long'[3], and 'Waiting for a Way Forward'[4], the Royal College of Obstetricians and Gynaecologists (RCOG) highlights the enduring impact of non-cancerous, often chronic and sometimes progressive, gynaecological conditions not being taken seriously by healthcare providers. They describe a lack of investment in training and service provision and the specialty being deprioritised during the pandemic, a decision which continues to have significant knock-on effects on waiting lists to now.

Whilst waiting lists for consultant-led care remains stubbornly long, RCOG explains that 'many women (are) now living with increasingly complex conditions and severe symptoms. A quarter of women who responded to our survey reported that they had attended A&E as a result of their symptoms, with more than 1 in 10 of those women going on to have emergency interventions, such as blood transfusions'. In the face of this situation, it is therefore essential that general practice is adequately equipped to support patients living with these conditions, both whilst they wait for secondary care interventions but also into the longer-term where those conditions are chronic in nature.

However, in a recent survey and series of focus groups, FTWW members made clear that they felt they did not receive adequate care within general practice. Some advised

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[1] https://executive.nhs.wales/functions/networks-and-planning/womens-health/the-womens-health-plan-for-wales/
[2] https://www.gov.wales/sites/default/files/publications/2022-02/quality-assurance-and-improvement-framework-2021-2022.pdf
[3] https://www.rcog.org.uk/about-us/campaigning-and-opinions/addressing-waiting-times-gynaecology/left-for-too-long/
[4] https://www.rcog.org.uk/about-us/campaigning-and-opinions/addressing-waiting-times-gynaecology/waiting-for-a-way-forward/

that their GP wasn't sufficiently knowledgeable about symptoms, treatment, or referral pathways, with others reporting negative attitudes and biases encountered in their healthcare appointments, where they felt symptoms were 'normalised' or minimised due to gender stereotypes, such as being 'over-sensitive', 'melodramatic', or the *perceived* tendency of women to somatisation.

If patient experience and outcomes weren't compelling enough to drive an improved offer for these conditions in general practice, the NHS Confederation's 2024 report, 'Investing in the 51%'[5] clearly demonstrates the economic benefits of improving care and support for menstrual and gynaecological health issues, evidencing how for every additional £1 of public investment in obstetrics and gynaecology services per woman, there is an estimated return on that investment of £11.

The report also describes the economic impact of ***not*** investing in women's health, with absenteeism due to severe period pain and heavy periods alongside endometriosis, fibroids and ovarian cysts estimated to be nearly £11 billion per annum, and unemployment due to unmanaged menopause symptoms costing £1.5 billion per annum and approximately 60,000 women in the UK their jobs. The report concludes with a recommendation that education and training for medical professionals be 'refurbished…specific to conditions that solely affect women as well as those that affect women differently'.

In Wales, we know that historic lack of focus on 'women's health' in medical training, and a concurrent lack of investment in services, continues to stymy patient access, with menopause a key example. Currently, many patients whose menopause symptoms could be managed appropriately in primary care (with a suitably prescribed HRT regimen) are, instead, referred to specialist menopause clinics for which the waiting time can now be as much as two or more years. It is hard not to attribute this issue to a lack of training and confidence amongst our GPs and an absence of advanced nursing practitioners in primary care focused on 'women's health'.

Similarly, patients living with chronic gynaecological conditions like endometriosis and adenomyosis, both of which have a similar prevalence to asthma or diabetes in women (ie around one in ten) can expect to experience the longest diagnostic delays in the UK at around 10 years on average. During this period, research undertaken in Wales shows that patients will have 26 GP appointments[6] to try to establish a cause of their symptoms (which, in turn, enables better management of the condition). However, many patients report that lack of knowledge about these conditions, their wide-ranging impacts on physical and mental health, and the GPs' lack of authority to refer to more specialised services out of area means that their care is fragmented and unsatisfactory, causing further health deterioration, and severely impacting relationships and employment.

[5] https://www.nhsconfed.org/publications/womens-health-economics

[6] https://www.gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf

For GPs and other healthcare professionals in primary care, there is clearly a training need therefore, but taking time out of practice to attend courses can be a huge challenge. Continuing professional development (CPD) is a requirement for GPs to maintain their licence to practice; however, amongst the panoply of topics available, how can we ensure that women's health specifically is prioritised when, so often, it is 'normalised'? Addressing historical misconceptions like these need to form part of initial medical training - but we also need to find a workable solution now that enables our primary care staff to undertake sufficient CPD to maintain and improve practice, whilst not impacting further on access to GP services. Health Education and Improvement Wales (HEIW)'s flexible CPD offer[7] is certainly a way forward, but we must ensure that women's health in its broadest sense is covered sufficiently, and modules routinely coproduced with patients / those with lived experience.

Whilst FTWW has been pleased to work both with the Welsh Government and NHS Wales on both Community Health Pathways and resources like the Endometriosis Cymru website[8] and symptom reporting tool (ESTR)[9], we are concerned that knowledge and usage of these platforms in primary care settings across Wales is inadequate. We hope that coproducing a webinar on the condition and how to use the tool with Health Education and Improvement Wales (HEIW) will see some improvement; however, we believe that both enhanced learning during medical training, and the inclusion of these conditions in the GMS contract, would undoubtedly result in a better offer to patients.

It is also important to point out that the third sector Women's Health Wales Coalition in 2022[10] identified there being no post-graduate women's health training courses available in Wales for practitioners who may wish to specialise in this area, and no incentivisation for healthcare professionals to either request or undertake one should such an offer exist. This is something we urge the Welsh Government to address as a priority with support from HEIW and the new HCRW-funded pan-Wales Women's Health Research Centre.

Whilst we recognise that the role of the GP is, by its very nature, to provide 'generalist' care, without adequate knowledge and training on menstrual and gynaecological health, and sex and gender-disaggregated medical research embedded into practice, we will continue to hear stories and read reports on women's needs not being met in healthcare settings. It is experiences like these that undoubtedly underpin many FTWW members' calls for more specialised 'women's health' clinicians to be available in primary care.

A training programme on women's health should also be open to allied healthcare professionals in Wales, including physiotherapists (enabling more to specialise in pelvic physiotherapy, which continues to be a hugely unmet need in Wales), advanced nurse

[7] https://heiw.nhs.wales/support/revalidation-support-unit/continuing-professional-development-cpd/
[8] https://endometriosis.cymru/
[9] https://endometriosis.cymru/srt/
[10] https://ftww.org.uk/wp-content/uploads/2024/07/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf

practitioners, and those working in mental health services. Indeed, when surveyed for the All-Party Parliamentary Group on Endometriosis in 2020, 90% of respondents[11] said they would like to access mental health support to help them manage the psychological impact of living with the condition. Many FTWW members continue to report high levels of anxiety and depression alongside their physical symptoms, with contributing factors including long diagnostic delays, limited and / or unsatisfactory treatment options, the absence of a cure, persistent pain, organ dysfunction, stigma, and infertility.

Increasingly, mental health support is seen as vital to enable patients living with chronic physical health problems to better manage the impact of their condition. For example, access to psychological therapies is recommended in NICE guidance on Chronic Pain[12], whilst CBT (Cognitive Behavioural Therapy) is included in NICE guidance on Menopause: Identification & Management[13]. However, given how stretched community mental health teams are in Wales, it is highly unlikely that any such offer would be routinely available to patients whose primary diagnosis is of a physical nature. The result is a continuing unmet need which sees a great many patients presenting to their GP for psychological care and support.

Further, as evidence suggests that it is more likely to be women and people assigned female at birth living with chronic illness and pain[14], depression and anxiety[15], much-needed new investment in mental health services delivered within primary and community care settings should incorporate elements of women's health. Practitioners should receive training not only on the physical and psychological aspects of conditions uniquely or disproportionately impacting women, but also on identifying and addressing gender bias within their own practice and how to adopt a trauma-informed approach. This would enable healthcare professionals to avoid adding to the existing burden of 'health trauma' that many women report, where they feel as though their voices aren't heard or taken seriously when reporting symptoms[16].

In terms of accessing primary care more broadly, many FTWW members describe how problematic making and attending GP appointments can be. We have heard discussions about how, pre-pandemic, it was easier to make appointments through a variety of mechanisms, such as online booking systems, telephone, and in-person. Since the pandemic, more and more patients describe an inaccessible and unworkable system of 'telephone roulette', where sick people have to sit on telephone lines for hours from 8am, with no guarantee of getting through or securing an appointment.

Patients describe having to recount sometimes highly personal symptoms to administrative staff who don't always have the knowledge or expertise to accurately

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[11] https://www.endometriosis-uk.org/sites/default/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf p.32
[12] https://www.nice.org.uk/guidance/NG193
[13] https://www.nice.org.uk/guidance/NG23
[14] https://www.iasp-pain.org/resources/fact-sheets/gender-differences-in-chronic-pain-conditions/
[15] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)31561-0/fulltext
[16] https://executive.nhs.wales/functions/networks-and-planning/womens-health/womens-health-in-wales-a-discovery-report/

report patient needs to medical personnel, sometimes resulting in no appointment being made, escalating ill health, and patients forced to go to A&E for care instead of seeing a GP. Some of our members have described administrative processes and attitudes as barriers to care, with neither practice staff or clinicians understanding or utilising the social model of disability and, instead, implementing systems that are exclusionary and / or continually questioning or judging people's access needs and preferences. The stress of needing to justify one's needs can actually end up making people more unwell, not least as they delay seeking help until their symptoms are unbearable or issues have reached crisis point. On the back of these experiences, members have called for everyone working in health and social care to undertake both social model and unconscious bias training, designed and delivered by those with lived experience.

In recognition of the diverse and often interconnected health and social care needs of patients, primary care is increasingly encompassing a wide range of services and providers, including 'social prescribing' link-workers. The role of the link-worker or equivalent is to assess patients' needs and signpost to third sector and community-based organisations to deliver support and activities as an adjunct to more formal statutory services. Many of FTWW's members have described third sector services as invaluable, even 'life-saving'. However, for this offer to be effective and sustainable into the future, more investment is required so that activities can be delivered equitably across Wales within communities. It is not acceptable to expect socially and economically disadvantaged people in Wales to pay for 'social prescriptions' where they are being offered as an alternative or adjunct to medical treatment, as this simply deepens inequity. Nor can we allow services of this nature to remain merely 'short-term projects' where their benefits are proven and people have come to rely on them to maintain personal wellbeing. Indeed, without proper, long-term resourcing, the concern is that people's safety nets will fall away, risking distress and further ill health.

As the workforce in general practice becomes more diversified, with physicians' associates, physiotherapists, nursing staff, community mental health teams, link-workers, and the GP amongst those situated in the primary care setting, patients report finding it increasingly difficult to keep track of appointments and services – a situation already well-evidenced in secondary care, where patients with complex needs will often be seen by multiple specialists whose interventions don't always join up. For unwell patients, some of whom will have additional barriers and access needs, the expectation that all patients will be sufficiently activated and capable of navigating systems, processes, and services, and facilitating communication between disparate medical teams is both unrealistic and inequitable. It is vital that healthcare providers in Wales look to address this issue as a matter of urgency, not least because difficulties understanding and managing one's own health journey often results in poorer outcomes for patients and inefficiencies within clinical settings.

It is issues like those described above that have driven the Royal College of General Practitioners (RCGP) to undertake work with its Patient & Carer Partnership Group to

better understand and advocate for the benefits of relationship-based care in general practice[17]. Certainly, for FTWW's members living with chronic health conditions and multi-morbidities, continuity of care, where one can expect to have a single named GP coordinating care and providing regular monitoring appointments, reduces both the trauma involved in continually repeating one's story and needs, and the stress and fatigue created by fragmented care.

Relationship-based continuity of care in general practice does not mean that other healthcare professionals shouldn't be involved in delivering services to / for the patient, but that the GP acts as a lead and conduit for patients to engage and get the best from multi-disciplinary teams. We would urge the Welsh Government and healthcare providers to work with community groups and patient advocates to look at the barriers and facilitators to making such a model commonplace, not least for those patients with additional needs and whose circumstances or characteristics make it more difficult to engage with general practice in the first instance. Without collaboration and coproduction built into the design of our healthcare services, we will continue to see certain individuals and groups excluded and left behind.

Recommendations

- **The general practice workforce and the growth of the multidisciplinary team**

  We recommend:

1) Serious consideration be given to developing the role of Care Coordinators who can assist patients with complex health needs to communicate with multiple medical teams and navigate and manage complicated pathways where lots of separate services may be involved, as informed by the CONCORD Study[18]

2) Further consideration and roll-out given to offering 'golden handshakes' to prospective medical students whose training costs would be covered if they commit to staying in Wales for a certain period of time post-training

3) Ensure that 'Women's Health Hubs' as set out in the 10-year NHS Wales Women's Health Plan[19] are coproduced with patients and third sector organisations in this space, and that general practice is fully integrated into them. As far as possible, we should be looking to avoid variation and inequity across Wales, so we recommend that a template 'model' of what the hubs 'look like', how they are accessed, and what they offer is clearly set out for providers,

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[17] https://www.rcgp.org.uk/representing-you/policy-areas/relationship-based-care
[18] https://www.ucl.ac.uk/epidemiology-health-care/research/applied-health-research/research/health-care-organisation-and-management-group/concord
[19] https://executive.nhs.wales/functions/networks-and-planning/womens-health/the-womens-health-plan-for-wales/ p.7

patients, and public, alongside coproduced key performance indicators and Patient Experience & Outcome Measures (PRE/OMS) so that the offer can be regularly and fairly evaluated. Should the Women's Health Hub model in Wales be successful, we would urge ongoing and recurrent funding be allocated to them, so that women's health is properly considered, improved, and prioritised into the future.

- **Training and continuing professional development**

  We recommend:

4) A detailed examination of how far and to what extent 'women's health', particularly issues relating to menstrual and gynaecological health, feature in medical training and work to address omissions identified

5) HEIW and the new Women's Health Research Centre in Wales to develop an accredited post-graduate Women's Health course for clinicians (including general practitioners) and other interested parties, with bursaries and other incentives available to ensure adequate take-up across Wales

6) Commencing as a matter of urgency a robust analysis and discussion of the role of 'specialist women's health' GPs and nurses in every practice or GP cluster, involving both patients and clinicians, to establish how far such an offer would improve the offer to women in Wales

7) Where GPs and Nurses with special interest in women's health already exist, support and resource the development of 'Train the Trainer' schemes to ensure adequate cover and succession planning

8) Ensure that all public-facing professionals in general practice undertake training on the social model of disability; equality, diversity & inclusion; identifying & challenging biases, and learn how to adopt a trauma-informed approach to their practice, all of which should be co-designed, delivered, and evaluated by those with lived experience.

- **The patient experience of general practice, including equitable access to care, effective management of patient demand, the quality of care, and public trust in the services provided**

  We recommend:

9) Examining models of primary care delivery in Wales where pharmacies are located on-site and within the practice itself so that pharmacists and clinicians

can easily and directly communicate with each other and patients, meeting their needs in a 'one-stop' set-up rather than patient going backwards and forwards between the two, further extending and complicating their patient journey / experience

10) Ensuring investment in training and integration of more advanced nurse practitioners in primary care, making an equitable offer to patients across Wales more feasible

11) Ensuring that the development and evaluation of Women's Health Hubs in Wales is coproduced with end-users and general practice, with clear communication, information, equity of access, and evaluation built into the model, and that longer-term funding for implementation and sustainability is made available

12) Coproducing initial and ongoing training with patients and their advocates, so that practitioners are well-used to working collaboratively, including as part of shared decision-making in practice. This would help to rebuild trust and confidence on the part of patients, particularly women and people assigned female at birth who have long reported unsatisfactory experiences in healthcare settings.

Thank you for your consideration of this submission to the inquiry on 'The Future of General Practice in Wales'.

Please contact info@ftww.org.uk for any further information required.