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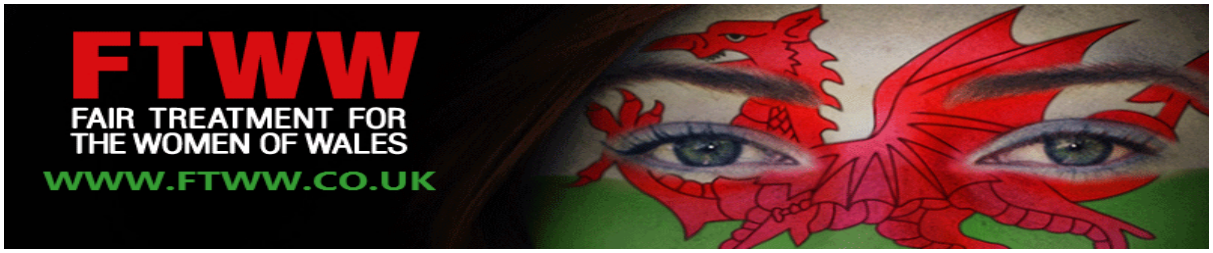
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Fair Treatment for the Women of Wales (FTWW)
Response from: Triniaeth Deg i Fenywod yng Nghymru



Fair Treatment for the Women of Wales (FTWW) is a third sector organisation set up to support, inform, educate, and advocate for girls and women in Wales who are suffering a range of health conditions and who are not receiving adequate (or fair) treatment. Many of the organisation's users feel that this is, in large part, due to the lack of specialist provision in Wales, and a system which currently doesn't routinely allow patients to choose and book those clinicians best able to provide care considered to be 'gold standard'.

FTWW aims to empower women to speak up with confidence amidst a medical and societal environment which often tends to privilege the male experience, sometimes dismissing women's symptoms and concerns as being 'psychological' in origin.

Currently, FTWW's focus is on endometriosis, a condition which affects one in ten women and yet which continues to be mired in misinformation and myth. With a similar number affected as by diabetes and / or asthma, the fact that diagnosis takes an average of 7.5 years is of great concern, particularly in Wales where GPs are frequently over-stretched as a result of staff shortages in many parts of the country.

FTWW surveyed its membership with regard to the consultation being carried out by Welsh Government's Health, Social Care and Sport Committee to establish priorities for the next 12-18 months and is pleased to share its findings as detailed below. We would also ask that the Committee read our report, 'Making the Case for Better Endometriosis Treatment in Wales' (available at http://www.ftww.co.uk/wp-content/uploads/2015/09/Making-the-Case-for-Better-Endometriosis-Treatment-in-Wales-Watermark-PDF.pdf), a copy of which has been previously sent to Welsh Government, and the health boards, for their consideration.

1) Integration of Health and Social Care services

1.1 It is important that policy-makers recognise that poor healthcare can ultimately lead to social services' intervention when that could have been avoided in many instances. In FTWW, many members report that diagnostic delays extending into years, and then the subsequent mismanagement of their conditions, has led to the breakdown of relationships and the development of mental health problems. The loss of a familial support network means that those women (and their children) then become reliant on social services to provide housing and other assistance.

1.2 It is absolutely essential that NHS Wales and the health boards listen to organisations like ours, groups who are on the ground and in touch with their membership every single day. We have important insight into those areas where diagnostic delays, excessive waiting lists, and poor patient

care in the interim, are having far-reaching and costly ramifications for patients, their families, communities, and the economy at large. However, it often proves difficult for third sector, user-led organisations like ours to navigate a way into the health boards, particularly those personnel who are in a position to act upon our insights in developing strategy.

2) Waiting Times

2.1 Our members frequently report waiting times for gynaecological services extending way beyond the 6 months recommended for an initial consultation – and then over a year for actual surgery subsequent to that. Unfortunately, lack of access to gynaecology doesn't make headlines in the way that access to cardiac care or orthopaedics does – partly because there is still a huge cultural reluctance to publicly discuss women's reproductive organs, and also because (as repeatedly suggested by our members) it tends to be dismissed as '*just* middle-aged women's problems'. Clearly this widely held public misconception is inaccurate in terms of age of patients but it also reflects the belief that non-cancerous gynaecological diseases are not life-impacting and therefore unimportant (and they don't directly affect men).

2.2 Our report into the treatment of endometriosis, 'Making the Case for Better Treatment of Endometriosis in Wales' tackles the subject of waiting times for gynaecology in quite some depth, with a particular focus upon how the mismanagement of this disease in the regular hospital setting is actually exacerbating the problem with waiting times (ie women on a merry-go-round of repeated ineffective surgeries with non-specialists rather than being referred immediately to a tertiary centre for a potentially one-off, gold-standard procedure). We would also draw attention to the need for investment in advanced laparoscopic skills for more gynaecologists in Wales, and the accreditation of additional specialist centres for the condition (at present there is only one-such centre in the whole of Wales – in Cardiff – which is woefully inadequate for the number of patients needing it). This would attract more appropriately qualified medics to Wales, thereby improving endometriosis patient outcomes, as well as reducing the current waiting lists for other gynaecological services.

3) Mental Health / Waiting times

3.1 Given that there is an established lack of mental health provision across Wales, it might be worthwhile exploring how third sector organisations could be better resourced (financially and in terms of additional training) to provide the support that many patients need – especially given the fact that not all mental health service users have serious / diagnosed psychiatric conditions but actually simply require a listening ear and more general support. For example, many of FTWW's members report being given anti-depressant medications inappropriately.

The reasons for this are many but include:

3.2 A widely held cultural perception that women who report physical pain / symptoms must be neurotic / over-sensitive / anxious / have mental health problems, inc. depression. There is considerable evidence to show that women's pain is taken less seriously than men's and treated less

aggressively. For example, there is much evidence to suggest that, in the emergency setting, it takes women twice as long to have their pain assessed / treated, and then with less powerful medication.

Women are more likely than men to have chronic pain conditions (such as endometriosis, adenomyosis, fibromyalgia, Chronic Pain / Fatigue Syndrome) which are not being diagnosed or managed effectively.

3.3 Some of women's pain conditions are gynaecological in origin, for example endometriosis, which requires surgical treatment. The failure to diagnose the condition in a timely manner, the shortage of gynaecologists in Wales specialising in excision of this disease, and the fact that referrals out of area to an accredited centre are not taking place, means that women are waiting years to access the treatment that could improve their lives and well-being. Consequently, they begin to suffer situational depression – the answer to which seems to be to dose them up with anti-depressants rather than seek to rectify the cause.

3.4 Lack of pain-management centres. Waiting lists for pain management can be a year or more and the GP does not have the time, expertise, or authority to create and monitor an effective pain management strategy for most female patients in need. Again, the solution seems to be to put patients on psychiatric medications because the easiest, most visible aspect of their suffering is the subsequent situational depression. It is rare that a referral to mental health services (for counselling / CBT / consultation with a psychiatrist) is made. This seems to evidence the fact that the GP does not consider these women to be legitimate 'mental health patients' – but might also indicate the unfeasible length of the waiting lists (in some instances, up to 4 years).

4) Primary Care

4.1 ***'…action is required to move the balance of care and resources – including workforce and funding - out of hospitals into the community so people only go to hospital where this is appropriate'.***

Whilst this is laudable, it is also essential for NHS Wales / policy-makers to appreciate that there are some conditions which cannot be ameliorated by lifestyle changes and which can only be effectively treated in the hospital setting. As already mentioned, most of FTWW's members have endometriosis, and a significant proportion of them describe going to the GP fifty or more times during the (average) 7.5 year wait for a referral to gynaecology. Clearly, this is not an effective strategy and comes down to an urgent need for re-education on this disease (something that FTWW is keen to work with health boards on providing). It also requires a change in culture within primary care when dealing with women's health.

4.2 In preparing for this submission, we surveyed our membership and the overwhelming request made was for GPs to take the time to *listen* to patients, girls and women being only too aware of their bodies from a young age. Our members also asked that GPs appreciate that social media / online support groups can be an invaluable source of information and that female patients may know a great deal more about the nature of their disease(s) and the best treatment(s) available than the GP (who, by his / her very nature has to be a generalist rather than a specialist). Our members

ask therefore that referrals to specialists are made in a timely manner, and not after years of attempted management in the primary care setting.

4.3 ***'The Welsh Government is committed to developing the role of 'clusters' - groups of GPs, working with other health and care professionals to plan and provide services locally'***

Part of this has to be NHS recognition and provision of alternative therapies. Many of our members have had repeated abdominal surgeries (often inappropriately / unnecessarily) and have developed considerable health problems as a consequence of this – not least post-surgical adhesions (which cost the health services a huge amount in terms of repeated (often futile) surgeries to lyse /cut them down, bowel obstructions, and pain management), nerve damage, and continuing pain. In an effort to reduce the need for long-term medication and on-going surgeries, both of which are very costly, our members ask that therapies like acupuncture, osteopathy, pelvic physiotherapy, and specialist massage be made available on the NHS, perhaps in purpose-built centres which incorporate GPs' and pharmacists' services or, if not practicable, at private clinics to which referrals could be made / NHS vouchers made available.

5) Efficiency within the NHS and modern management practices

5.1 ***'The Committee could examine the potential for securing business and industry skills to work with NHS Wales in looking for efficiency opportunities, in both support and clinical services'.***

It is our belief that the best efficiency opportunities could be established not so much by looking to 'business and industry' but by pro-actively seeking out, listening to, and working with, user / patient-led organisations who can see, first-hand, exactly where there are issues, and offer up pragmatic solutions. At the moment, it is incredibly difficult for us to get our voices heard, even when we are making suggestions that have enormous money-saving potential for the NHS in Wales. There needs to be a direct and widely publicised point of access for organisations like ours to share our expertise, and there needs to be improved communication so that we know our suggestions are being discussed further and acted-upon, as far as possible, involving and consulting with us all the while.

5.2 As mentioned already, our report into endometriosis care in Wales provides some analysis of where there are potential efficiency savings to be made – but there also needs to be a realisation that long-term investment is essential if we are to be able to move away from a culture of quick (inefficient and costly) fixes.

6) Neonatal services

6.1 FTWW would like to see much more of an emphasis placed on ante-/post-natal mental health by Health Boards, with a campaign for it to be deemed of equal status to physical health during and after pregnancy. This also means that any consultations in relation to proposed changes to maternity services in Wales should place the impact of those changes to women's mental health as a top priority rather than an afterthought.

6.2 ***'The Committee could undertake an inquiry to monitor progress, specifically looking at ongoing concerns about staffing and the sustainability of services'.***

A key part of this has to involve consulting patient groups as to where they see priorities lying. In particular, a focus on training health professionals to be aware of the warning signs / risk factors for developing mental health problems during and after pregnancy (such as hyperemesis gravidarum and resultant mineral deficiency; pre-existing anxiety conditions, etc) so that early intervention and support is available to those women, thereby potentially reducing the likelihood of severe post-natal psychosis. A great deal of support is available to pregnant women / new mothers from user-led organisations but provision is piece-meal and under-funded. Given that mental health services are already the poor relation in our NHS, it is incumbent upon policy-makers to properly resource and utilise such organisations, many of whom are far better placed to provide the listening ear, empathy, and informal support that is all many women need in order to manage their symptoms.

6.3 However, should women require more formal, medical interventions, these should also be readily available (such as local in-patient mother & baby units) in conjunction with third sector provision. There needs to be much more targeted investment and partner-working across Wales in terms of promoting mental well-being both during and after pregnancy. It is widely recognised that supporting mothers and their babies early on massively reduces long-term costs to the NHS / social services.

7) Final thoughts

7.1 Since compiling our report into endometriosis treatment in Wales, it has come to our attention that not only are patients in Wales not routinely able to access care across the border, in England, they are also prohibited from seeking treatment under other health boards within Wales. This is quite patently unfair to patients. If it could be guaranteed that all forms of treatment were identical across Wales, this might be a workable system but, realistically speaking, this is unlikely ever to be the case: there will always be discrepancies, and medics more suited to a patient's needs may well be practising just a few miles away, in another part of Wales – or, indeed, in England.

7.2 It cannot be in the patient's best interests or well-being to force them to undergo potentially inappropriate or unsatisfactory treatment within their own health board, simply because that is the (highly restrictive) strategy employed by NHS Wales. Indeed, in England, there are mechanisms in place which aim to give patients far more of a voice in devising their treatment plan: both a patients' charter and a 'choose and book' system exist so that patients may select a hospital or surgeon according to their level of expertise, waiting times, or location. Furthermore, patients in England are able to view individual hospital departments' (even surgeons') outcomes, so as to give them the opportunity to make a more informed choice. The fact that NHS Wales has not followed suit with any of these mechanisms suggests that patient autonomy is not at the forefront of its agenda when, in actual fact, according to our members, empowering the patient in this way can dramatically improve their sense of well-being.