Written evidence submitted by Fair Treatment for the Women of Wales (MRS0325)

As the only patient-led voluntary organisation in Wales dedicated solely to women's health equality, with an online membership approaching 1200 women living with chronic or recurrent, often invisible health conditions, it is vital that we make both UK Government and the public at large aware of the issues facing this specific, often marginalised, community during Covid-19.

The existence of FTWW's online forum has enabled our community to share their experiences and discuss those most pressing issues facing them as lockdown continues. These are described in the following report.

We would ask the UK Government to take the following into account:

- **Women make up around 51% of the population**
- **More women than men are living with chronic illness, both physical and mental**
- **Health conditions affecting women tend to incur a significant diagnostic delay**
- **Women require more clinical interventions as a consequence of pregnancy and childbirth**
- **Women, including disabled / ill women, are more likely to be care-givers, single parents, and on low incomes**

Our report examines, and makes recommendations on, 6 specific areas:

- **The impact of previous Diagnostic Delays**
- **Access to Clinical Interventions / Medication**
- **Hydroxychloroquine for Auto-Immune Disease Patients**
- **Pregnancy-related issues**
- **Daily Living**
- **Mental Health**

Our findings show that these issues have considerable significance during the Covid-19 crisis, including:

Women are being disproportionately affected by the cancelling of medical appointments, hospital procedures or operations, and difficulties accessing medication

Women with, as yet, formally undiagnosed health conditions are finding it hard to take advantage of the provisions put in place for those considered 'vulnerable', including supermarket or pharmacy deliveries

Pregnant women are at potential risk of injury and trauma as a result of restricted services

Disabled / ill women are more likely to be on low incomes and find it hard to pay increased utility and food costs

Women are at increased risk of mental health issues as a consequence of ill health in combination with the additional practical and psychological pressures of lockdown.

1 Diagnostic delay

Women are disproportionately affected by diagnostic delay, whether of gynaecological conditions or diseases which affect men as well. There is a great deal of research showing that women's symptoms are often normalised / not taken seriously, or that the way they present is simply not regarded as 'typical' because the diagnostic model is based on male symptomatology (such as with heart attacks).

80% of those living with auto-immune conditions are women, with a diagnostic delay of 5 or more years; endometriosis, a condition which affects 1 in 10 women mainly of reproductive age takes an average 8.5 years to diagnose in Wales (7.5 in England / Scotland). As many women as men are living with cardio-vascular disease and yet research by the British Heart Foundation (https://www.bhf.org.uk/informationsupport/heart-matters-magazine/medical/women-and-heart-disease) shows that women are more likely than men to die from heart attacks, due to delayed diagnosis and poor treatment.

In everyday life, the issue of diagnostic delay can pose very real problems not only for health but also for employment and financial security. During Covid-19, women are finding it also prevents their being formally recognised as 'vulnerable' with which comes additional support, including special slots for supermarket shopping, and home delivery of supplies or medications.

Another significant issue is that, due to the widespread lack of appreciation over how women present with conditions like heart attacks, they may see concerns over contracting or spreading Covid-19 as another reason to delay help-seeking. Inevitably, this will have implications both for survival and / or long-term prognoses. It is vitally important that the NHS is prepared for an influx of very unwell patients following the lifting of lockdown, and that women's symptoms are not dismissed.

2 Access to clinical interventions, including medication

Women who would ordinarily have regular medical appointments, whether they be reviews of medication, procedures such as hormone injections to manage gynaecological conditions, or iron transfusions for anaemia, for example, are now struggling to access these appointments, for a number of reasons.

Understandably, routine in-person appointments can, in large part, no longer be accommodated; however, despite tele-conferencing being made available in many circumstances, our respondents have reported a lack of consistency around this provision.

We must not discount the fact that digital technology isn't always a viable option for people, especially for those living in remote, rural areas without a reliable internet connection. For women (who are often on lower incomes and / or may be victims of abuse) access to technology may be unaffordable or even unsafe.

Whatever the reasons for appointments with healthcare providers not routinely taking place, our respondents report finding that they're now expected to manage their health conditions with sub-optimal or no medication. Some are trying to eke out existing supplies; others are being forced to withdraw from medical management altogether; still others may be forced to pay privately for their medications, sourcing them from suppliers whose legitimacy cannot be guaranteed. This will inevitably have a significant and detrimental impact on prognoses.

As mentioned, not everything can be done remotely. This includes hospital-based procedures and operations. Many patients now find themselves unable to have these essential appointments, whether that be because they're no longer available, as healthcare providers are redeployed or as the NHS seeks to reduce in-person contact, or because patients themselves are vulnerable and self-isolating.

Indeed, some women report now being reluctant to seek help, either due to concerns about burdening their healthcare providers, or because they're afraid of contracting Covid-19 should they be required to enter a clinical setting. Either way, we are hearing from patients who are choosing between no intervention / medication, continuing with medication without any form of review (thereby putting themselves at risk of harm), or, as they describe it, 'putting (themselves) in danger by entering a hospital or GP practice'.

For a not inconsiderable number of respondents, their waiting times will now extend into years. Patients appreciate the prioritisation of those affected by Covid-19, however, a lack of information about how to manage symptoms in the interim or where this leaves them in terms of waiting lists is proving highly problematic and compounds what is already a very stressful situation.

At FTWW, our chief concern is that the longer patients have to go without being able to consult with their medical team(s) or consultants, particularly in terms of evaluating medications, accessing essential interventions, or interim self-management, the more likely it is that individuals will need to be admitted to hospital in an emergency situation unrelated to Covid-19. Emerging from the lockdown, we also envisage those with chronic illness requiring expedited access to specialists as a result of worsening symptoms / prognoses.

3 Availability of Hydroxychloroquine

Most people with auto-immune conditions, such as Lupus, Sjogren's, Undifferentiated Connective Tissue Disease (UCTD) or Mixed Connective Tissue Disease (MCTD) are women. In fact, it's estimated that 80% of those living with an auto-immune condition will be female. Many of these are taking hydroxychloroquine; it is often the basic building-block of a long-term drug regimen for such patients. As a result of its being posited as a possible 'cure' for Covid-19, there are now very real concerns on the part of respondents that it will be bought up in large quantities, depriving those patients who have an established need for it.

4 Pregnancy

i) Early Pregnancy Units (EPUs)

Reluctance to utilise emergency services and, indeed, a prevailing sense of being discouraged from visiting clinical settings during this crisis means that, sadly, increased numbers of women will miscarry at home, some of whom may well require urgent medical help for ectopic pregnancy, infection, and / or severe bleeding.

Current restrictions on partners accompanying pregnant women to clinical settings could be seen as essentially forcing them to experience any potential loss of their baby/ies by themselves. We would urge providers be as flexible as possible in these circumstances, or at least consider how remote technology could be utilised to enable birth-partners to be 'present' at such times.

ii) Foetal Monitoring

Non-essential maternity appointments are being cancelled or conducted over the phone, including 16-week appointments where baby's heartbeat is monitored. This could result in potentially fatal issues, such as infection, being missed. Further, for those who have experienced recurrent or previous baby loss, a scan can be a terrifying prospect. With women now expected to attend these procedures alone, there lies a very real risk of related trauma.

iii) Birth and Birth Trauma

With birth partners now only allowed to attend during actual labour, and the added complexities brought to both the delivery suite and pregnancy / maternity by Covid-19, it seems inevitable that trauma and associated mental health issues will increase exponentially for families and staff. It is vital that measures are taken now to prevent this as far as possible, recognise it when it occurs, and have mechanisms in place to deal with and treat it.

iv) Post-Birth

Current guidance dictates that midwives do not, as far as possible, carry out home visits. The potential impact of this for the well-being of both mother and baby is huge, including missing out on breastfeeding support, missed opportunities to spot domestic abuse, and not picking up on any maternal mental health issues.

v) Maternity-related issues outside of clinical settings

Social distancing for pregnant mums has significant financial implications. Currently, Government guidance makes it a choice for mums rather than an obligation for employers to protect the health and jobs of their employees. As a result, many pregnant women are on Statutory Sick Pay (SSP) instead of being furloughed. This could impact on their eligibility for Statutory Maternity Pay (SMP) if it coincides with the calculation period for SMP. It is also forcing many expectant mothers to choose between their economic security and their own / babies' health.

vi) Fertility Treatment

As with all elective procedures, fertility treatment has been cancelled. For those women who are nearing the usual cut-off point age-wise, whilst this has been extended, there are very real fears about the effect this will have on the success of any future treatments. The mental health impact of this cannot be under-estimated.

5 Daily Living during Covid-19

i) Childcare

With women making up the vast majority of people responsible for looking after children, the impact of lack of childcare or schooling could have significant health-related repercussions for those who are already disabled / living with significant health conditions. It's vital that Government does all it can to issue guidance and implement practical support for these women.

ii) Bills

Disabled women / women living with chronic illness tend to be amongst the poorest in our society. The current crisis inevitably means that utility and food bills will rise as people are expected to use more water, electricity, and gas to do increased amounts of washing and cooking. This needs to be considered urgently, as more women accrue debt in trying to cover these bills. At the very least, child benefit should be increased to £50, so that those with children and most badly affected can more easily afford the rising costs of lockdown.

iii) Shopping

Across the UK, lists of vulnerable people have been collated, based on pre-existing diagnoses / treatment, enabling those people to be considered priorities for shopping and / or furloughing. The list is fraught with inconsistencies and gaps, with some health conditions not being included despite treating medical professionals advising otherwise.

Given the diagnostic delay that so many women's health conditions incur, it seems inevitable that women in particular will be affected by how such a list is being drawn-up. Thus far, it has resulted in a significant number of people not being able to utilise the benefits of being on the list when, clearly, they should be able to do so.

Self-registration would reduce the numbers of vulnerable patients using up limited resilience to queue for shopping at a time when the risks to them of doing so are exceptionally high.

It is also important to be aware that the current limits imposed on purchases of individual items, whilst understandable and logistically possible for the 'well', pose considerable challenges for those on restricted diets as a consequence of their health condition(s). A database where people can outline their specific needs would help to ameliorate this issue.

iv) Exercise

For those with impairments that affect mobility or cause fatigue, 'exercise' can be a problematic term. It would be more inclusive to refer to 'fresh air and exercise', thereby reducing the likelihood of those with invisible illness being targeted should they need to stop

and rest during any outdoor periods, or wheelchair-users facing comments about 'not needing exercise'.

v) Clarity of information re 'shielding'

As described in the section on 'shopping', the lack of UK-wide consistency around 'shielding letters' and 'vulnerability lists' is proving extremely problematic for those living with significant health issues and multi-morbidities, the majority of whom will be women. In Wales, we know that there are still people waiting to receive official letters confirming their need to shield.

As already outlined, Government's own list of conditions to be considered 'high risk' is not comprehensive; patients seeking advice from their GP practice regarding being added to said lists are finding it difficult to get the assistance they need. These letters are essential documents, not least required to show employers, because those women who need them may be key-workers (around 80% of key-workers are indeed, women) and called into work, despite their health condition(s) making them vulnerable to infection.

Furthermore, the UK media can sometimes misrepresent the situation, unintentionally reporting England-only interventions as being applicable to all; this confusion is harming patients in the devolved nations who don't know where to turn for accurate and nation-specific guidance. Our respondents report feeling disenfranchised and disempowered.

6 Mental Health impacts

Whilst women, particularly disabled / unwell women, are isolated and without access to their usual forms of support, medication, or intervention, it seems inevitable that the numbers experiencing mental health issues will rise.

We already know that women are more likely than men to be living with a mental health condition. For example, young women are at an increased risk of self-harming behaviours, including eating disorders, whilst specialist services to treat them are not consistently available across the UK.

We already know that women of menopausal age, predominantly responsible for household chores and care of relatives, are at increased risk of death by suicide and that HRT has, up to now, been in short supply.

We also already know that women experience unacceptably long waits for diagnosis and treatment, particularly when it comes to gynaecological conditions, resulting in consequent depression and anxiety. It is vital that Government and service-providers begin considering and exploring measures now, to ameliorate the long-term mental health consequences for women of Covid-19.

In conclusion:

- It is important to note that, whilst most women living with chronic or recurrent illness / long-term health conditions are often stoical and already accustomed to both self-management of symptoms and some element of isolation, UK Government must do

all it can to avoid additional harms being done to current and future generations

- It is women who carry the majority of responsibilities where child-rearing is concerned; it is they who must be supported if we are to avoid the well-established long-term implications of adverse childhood experiences. This is particularly pronounced for those women who are both living with health conditions and who may be at risk of developing / worsening mental health conditions. For both them and their offspring, we must listen to those being impacted and act now

- Ideologically, it is hoped that the now regularly expressed concern for people being isolated within their homes will continue for those permanently housebound by illness once 'normality' resumes. It is also hoped that friends, families and employers will, in future, appreciate how challenging life is for people with chronic illnesses and impairments, and make more effort to be inclusive. This should include the continuation and further development of reasonable adjustments, such as remote working, when, previously, disabled people were often denied these measures. Respondents were united in hoping that positive changes to general perceptions, attitudes, and practises would continue beyond Covid-19

- We would ask that all data collected throughout the crisis be disaggregated both according to sex and also other protected characteristics, so as to explore – and learn from - the intersectional impact of Covid-19

- Coming out of the crisis, we shouldn't necessarily be attempting to 'go back to how things were'; inequalities were rife – any future society should be re-established with mechanisms in place to minimise them, going-forward.

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