

**The Health Foundation Covid19 Impact Inquiry: Exploring the Pandemic’s Implications for Health and Health Inequalities**

**FTWW Response, December 2020**

**FTWW: Fair Treatment for the Women of Wales is the only patient-led voluntary organisation in Wales dedicated solely to women’s health equality. Our membership spans the length and breadth of Wales and encompasses women living with a wide range of chronic, recurrent, often invisible health conditions. All of our reports are rooted in the lived experience, with women’s voices and experiences sought via our online forum.**

**This report is our response to the Health Foundation’s inquiry, looking at the impact of Covid-19 and governmental responses to it, on those health issues and inequalities experienced by women in Wales. It is formatted in response to four questions raised by the Health Foundation, as follows:**

1. **The impact members’ existing health status has had on their experiences of Covid-19**
2. **How members’ individual, social and economic circumstances has affected their experiences of COVID-19**
3. **The impact government and societal responses to the pandemic have had on members’ health**
4. **How the government and societal response has affected members’ social and economic circumstances and the potential implications for their long-term health.**
5. ***The impact members’ existing health status has had on their experiences of COVID-19***

Delayed diagnoses and lengthy waiting times for largely inaccessible specialist services is an issue of significant concern in Wales. As a women’s health equality organisation providing support and advocacy across the region, historical bias which sees women’s symptoms often underplayed and associated services under-invested has been highlighted by Covid-19 and is having a huge impact on health outcomes for women across the country.

Westminster Government’s All-Party Parliamentary Group (APPG) for endometriosis published a report in October which showed that Wales had the worst diagnostic delay out of all 4 nations, at over 9 years (https://www.endometriosis-uk.org/sites/default/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf). Research in 2018, conducted by Cardiff University, showed that it takes an average 20+ GP appointments to get a referral to gynaecology to formally diagnose the condition (https://gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf), with women reporting that their symptoms are often dismissed or misattributed to other conditions. Covid-19 will likely extend this diagnostic delay still further, with women reluctant to visit their GPs or persevere in pushing for a diagnosis. Instead, many are trying to manage worsening symptoms at home, with little to no medical support. Disease progression and ultimately poorer outcomes are expected.

80% of those living with auto-immune conditions are women, with a diagnostic delay of 5 or more years. In Wales, there are no specialist centres of excellence for conditions like lupus. As with endometriosis, the longer patients go without any clinical intervention the worse symptoms and outcomes will be.

As many women as men are living with cardio-vascular disease and yet research shows that women are more likely to die from heart attacks due to delayed diagnosis and poor treatment.

Autistic women have often had to wait until adulthood to be formally diagnosed, due to traditional diagnostic models being based on male presentation. Messaging and strategy during the pandemic and associated lockdowns have undoubtedly had a significant impact on neurodiverse communities but for those without a diagnosis and formal support in place, there has been a particularly pronounced negative impact on mental and physical health which will likely have long-term impact on those people’s lives.

Indeed, as we explored in our June report, the issue of diagnostic delay has consequences far beyond the extended suffering of symptoms, disease progression, and poorer health outcomes. It also has significant socio-economic impacts, making it more difficult to continue in education or employment, make a case for reasonable adjustments, or claim certain social security benefits. The over-reliance on the medical model of disability has also made it difficult for women struggling to get a diagnosis for their symptoms to take advantage of those mechanisms created to better support people through the pandemic, including special slots for supermarket shopping, or home delivery of supplies or medications.

One of FTWW’s members said, ***‘Having an existing health condition, and leaving hospital just two weeks before lockdown absolutely increased my anxiety around Covid-19…There was a definite drive to discharge patients as quickly as possible. Then on top of that, there were difficulties accessing the healthcare and medications that I needed. I felt lost and really believed I had nowhere to turn’.***

For those women whose impairments / health conditions are particularly severe and who ordinarily rely on care from external sources or family, there have been significant challenges in ensuring continuity of that care during lockdown. Some, on direct payments from their local authorities, have been expected to both source and fund PPE themselves with no additional monies to do so. Others, in abusive circumstances, have found themselves in lockdown with a perpetrator who is also their carer. Very little has been mentioned about the additional barriers to seeking help and refuge that being disabled or chronically ill poses.

As has been widely reported, the pandemic has seen a wholescale exacerbation of existing inequalities – and those plaguing women’s health and related services has been no exception. During Covid-19, women in Wales and beyond have found that diagnostic delay, lack of care plans or pathways, and the low priority historically given to service development for the health conditions which predominantly affect them, has seen them particularly hard-hit by cancellation of already scarce appointments.

Prior to the pandemic, women’s health services in Wales, particularly those requiring specialist intervention, were inadequate and over-subscribed as a result, assuming they existed in the first place. The pandemic continues merely to add to existing long delays and barriers to accessing care out of area. Surgery for benign gynaecological conditions is one area where it seems unlikely that services will fully resume any time soon, something that many of FTWW’s members feel is because women’s health, symptoms, and pain are so often under-estimated and their concerns diminished.

Another significant issue is that, due to lack of clarity over how women present with conditions like heart attacks, and the cultural tendency to ‘normalise’ gynaecological symptoms and pain, many women have expressed 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. Now, more than ever, we have seen women reaching out for advice and support as they seek to manage their symptoms at home.

Another FTWW member reported that her existing health conditions had a massive impact on her experiences during Covid-19: ***‘I have post-traumatic stress disorder, bi-polar disorder, and suffer from psychosis…I have reached crisis point with my mental health on multiple occasions and the experience of just having the crisis team on the phone rather than coming to visit in person has prevented me from reaching out for help. I have had two admissions under mental health and was discharged before I was ready with little to no support at home following discharge’.***

1. ***How members’ individual, social and economic circumstances has affected their experiences of Covid-19***

Prior to the pandemic, our discussions with women across Wales and the UK demonstrated that there was scarce understanding or accommodation of women’s health and wellbeing needs in the workplace.

Many women with menstrual health conditions, including menopause, or mental health issues tell us that they are unable to talk openly to their employer or colleagues about symptoms or reasonable adjustments, with some having to leave work as a result. Undoubtedly, therefore, when considering who to put on furlough or, worse, make redundant, women with pre-existing health conditions or who were pregnant, were amongst the most likely candidates.

Given that women already bear the brunt of most caring responsibilities, are most likely to be a single parent, and most likely to be on lower wages, Covid19 has exacerbated existing financial challenges. For disabled women, including those living with chronic / recurrent health conditions, there has been a particularly pronounced negative impact, as they were amongst the poorest in our society even before Covid19.

The additional stress that the pandemic has put on already stretched financial circumstances for these communities may well see exacerbation of health conditions, with women unable to afford or access measures that they may have taken previously to help manage their condition(s), including counselling services, physiotherapy or other manual therapeutic interventions, targeted exercise programmes, or managing special dietary needs.

There has been a wholesale assumption that everyone can work from home during the pandemic, even though, previously, disabled workers were often denied this option. For those for whom home-working has been possible, there are both pros and cons. For some disabled workers, it has reduced physical barriers to the workplace but digital isn’t always a solution, depending on the nature of the person’s impairments. Furthermore, there are both practical considerations which can make home-working more difficult for people on low incomes, such as finding a suitable space within the home and the additional costs attached to using a home phone, electricity, or even being forced to purchase additional technological devices to enable all family members to use them as required. For some disabled people, the cost of acquiring a suitable ergonomic chair for desk work has been untenable, whilst others fear that sweeping assumptions will be made about capacity.

One FTWW respondent said: ***‘I’m in pain whether I’m at home or in work – it makes no difference. I worry that a move towards digital will see me being sanctioned (by the DWP) for not seeking work I can do at home’.***

Women have had additional pressures, both financial and in terms of juggling family responsibilities, many of which have – stereotypically - reverted to them during this time. For those women also living with chronic and / or recurrent health conditions and impairments, many of whom are currently unable to access the necessary treatment(s), this period has been one of considerable stress and hardship.

One of FTWW’s respondents said: ***‘I feel blessed that I have been able to keep my job throughout this, and my line manager has been so kind with allowing me a phased return to work. But then I have also felt invisible. Working from home has meant that no-one has seen my pain or my struggles…I have also worked when feeling really unwell as, without the commute, do I have a right to call in sick?’***

Another of FTWW’s members spoke of the often invisible hardships experienced by those who live alone with chronic health issues and how Covid-related lockdowns have exacerbated both mental health symptoms and additional isolation and loneliness, ***‘I struggle to leave home alone due to my mental health conditions and the physical impact my physical conditions have. I have had to rely on others to do my shopping and collect my medications due to the shops preferring you to shop alone. This, in combination with not being allowed people in my home, has led to a lot of feelings of loneliness’.***

1. ***The impact government and societal responses to the pandemic have had on members’ health***

At the launch of the APPG report on endometriosis care, a commitment was made on the part of NHS England to recommend that all Trusts contact women on waiting lists for (postponed) routine operations to offer interim support and management. We reached out to Welsh Government and NHS Wales to ask that it adopt a similar approach. Their strategy remains one of allowing individual health boards to decide for themselves where their clinical priorities lie, and how to communicate those to patients.

For those services which are typically under-resourced and not considered priorities – benign gynaecology being a key example – there continues to be no meaningful resumption of care and no consistency across Wales in terms of messaging or communication with patients. The result has largely been one of neglect of women’s health, with many patients slipping through the net and having little to no medical support for the past year and, potentially, beyond.

One of FTWW’s respondents said, ***‘Lockdown has certainly impacted my mental health and feelings of isolation. My pain appointments have been cancelled. Certain medications have been out of stock, pelvic physio was delivered over the phone. It’s been one nightmare after another’.***

Where women’s health is concerned, there is a legitimate concern that if and when health services begin to resume, pre-existing inequalities will rear their heads again as governments and health boards look to re-prioritise need and investment. In primary care, despite the numbers affected and costs to the economy incurred, conditions like endometriosis and menopause are still not given the funding and status of ‘enhanced services’ awarded to conditions like diabetes or COPD for example. This is unlikely to change as attention turns to managing Long-Covid and other chronic health conditions for which diagnosis and pathways already exist.

FTWW’s members generally feel as though their experiences haven’t really factored-into public discourse around those particularly badly affected by the pandemic, partly because many of them are living with ‘invisible’ health conditions, rendering them equally invisible as human beings in media coverage, public health messaging, government / local strategy, even research projects. Equally invisible have been those women using maternity services during the pandemic, a not insignificant number of whom will have received bad news at pregnancy scans, or lost their babies at home, alone. The apparent lack of attention paid to these issues speaks to the sense so many women have that their health issues are not a pressing concern to decision-makers, the media, or the public at large.

The tendency on the part of government and decision-makers has, unfortunately been rather divisive, focusing on specific characteristics rather than adopting a more intersectional and social model approach. As a consequence, feelings of isolation have deepened, potentially resulting in poorer mental and physical health in the long-term (unless tackled now) and subsequent socio-economic hardship. The cycle of deprivation seems almost unavoidable.

The voluntary sector has tried to step in to fill some of the gaps in public services, at least in terms of emotional support and advocacy, but whilst governments have been quick to signpost citizens to the sector at this time of crisis, they haven’t followed this up with improving access to long-term, sustainable funding. As a result, the sector’s offer will inevitably be piecemeal and not necessarily sufficiently long-lasting to cope with longer term demands. With so many people now relying on the voluntary sector for support, the lack of sustainability – an issue raised repeatedly and strenuously in the past – now poses a very real risk to the wellbeing of service users.

1. ***How the government and societal response has affected members’ social and economic circumstances and the potential implications for their long-term health***

At a UK level, legacy benefits, of which long-term sick and disabled are most likely to be recipients were not increased in line with Universal Credit – this despite the fact that Government-issued instructions have led to higher costs, such as utility bills for the increased amount of washing (hand, clothes, PPE), heating as we enter the winter period, and minimum spend amounts for home shopping deliveries.

Rules around the wearing of masks, whether disposable or re-useable, have financial costs attached to them which haven’t been considered in the development of strategy. The poorest people in our society tend to be those in the worst health and the most likely to suffer isolation and loneliness – they are also the least able to afford the PPE which is now a requirement for entering public spaces. Consequently, the ill health associated with social isolation is being exacerbated by legislation designed to protect them.

When it comes to health services, the wholescale move away from in-person provision has had dire consequences for those awaiting operations considered ‘non-urgent’. For those patients suffering chronic – and escalating – pain, accounts are sobering, with many of them reporting a dramatic deterioration of quality of life, not only for themselves but also their families. For women, this is particularly pronounced, as they are most likely to be providing care for elderly relatives as well as their own children. There has been a real lack of sensitivity in describing people’s healthcare needs as ‘non urgent’, as we see physical and mental health experiencing such a downturn as to render full recovery implausible.

One of FTWW’s respondents said, ***‘This feeling of loneliness is as a direct result of the guidelines put in place by the government. I am now facing an exceptionally long wait for…specialist (care). I’m facing three years of an indwelling catheter, constant daily pain and decreasing mobility with no end in sight. 3 years is just the ballpark I’m currently hoping for’.***

At a Wales level, there is very much a determination to allow local authorities and health boards the autonomy to design and deliver services for their communities. Whilst there are certainly benefits to this, at times of national crises, there will always be a risk of confused messaging, variation, and inequality in terms of what citizens can expect from public bodies. One of example of this was the differing ways and timeframes in which local authorities dispersed free school meal allocations to those families in receipt of them. Some chose to ask families to travel to schools to collect packed lunches, whilst others immediately issued financial assistance. Amounts differed, so too did the dates at which they commenced. The result was additional hardship and anxiety for certain vulnerable populations.

What is perhaps most remarkable to the network of women and disabled communities we encounter across the UK is how pre-existing legislation and strategies seem to have taken a back-seat during the pandemic. Many of those affected see the various principles of the Equality Act, the Social Services & Wellbeing (Wales) Act, and the Wellbeing of Future Generations (Wales) Act as not necessarily being universally implemented, and Equality Impact Assessments not always conducted in a consistent and meaningful fashion.

These decisions are ostensibly to protect the most vulnerable (although many don’t see themselves represented either by this word or the messaging / campaigns that have gone with it) even though those mechanisms were actually there to benefit the marginalised and ‘vulnerable’ in the first instance.

The result has been that disabled, and chronically ill people have been amongst the worst hit by the pandemic, making up 69% of Covid-related deaths in Wales thus far. This wasn’t inevitable but, in most instances, avoidable if only contingency plans and measures had been in place to ensure co-productive strategy-making was the norm and if we had already made the tackling of inequalities at the heart of every decision beforehand.