

C 49

Ymchwiliad i effaith Covid-19, a'r modd y mae'n cael ei reoli, ar iechyd a gofal cymdeithasol yng Nghymru
Inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales
Ymateb gan Driniaeth Deg I Ferched Cymru
Response from Fair Treatment for the Women of Wales

2020

The Impact of Covid-19 in Wales: A Women's Health Perspective

FTWW

FAIR TREATMENT FOR
THE WOMEN OF WALES

WWW.FTWW.CO.UK

TRINIAETH DEG
I FERCHED CYMRU



FTWW

9th June 2020



The Impact of the Covid-19 Outbreak and its Management on Health and Social Care in Wales: A Women's Health Perspective

June 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 document is both our response to Welsh Government's Health and Social Care Committee's Inquiry and a follow-up to our first report, published in April, *'The Impact of Covid-19 on Women's Health in Wales'* <http://www.ftww.co.uk/wp-content/uploads/2020/04/FTWW-Report-on-The-Impact-of-Covid19-on-Womens-Health-in-Wales.pdf>

Our first report looked at the various ways in which historical diagnostic delay for women's health conditions could impact on the support available to them during Covid-19; accessing clinical interventions and medication; the availability of hydroxychloroquine; pregnancy; daily living during Covid-19, and the mental health impacts of the crisis.

This second report examines those women's health-related issues and concerns which are yet to be resolved by Welsh Government. It will also look at how we as a nation might begin planning our emergence from the crisis so as to ensure that women's health needs are properly accommodated both in the short and long-term.

With Welsh Government's legislative aim to put the Well-being of Future Generations front and centre of decision-making, and the preventative agenda enshrined in its prudent healthcare principles, hearing women's voices now – and working with them going forward – will ensure that services are fit for purpose and our nation's health improved as a result.

We sought our members' views on the following 5 themes; their responses have been grouped under each theme:

| Contents | Page |
|--|-------------|
| Theme 1: The impact of cancelled medical and hospital appointments or procedures | 3 |
| i) Cancelled hospital appointments / procedures | 3 |
| ii) Cancelled screening tests | 4 |
| iii) Delayed fertility treatment | 4 |
| iv) Lengthy waiting times | 5 |
| Theme 2: Accessing the GP or primary care services | 5 |
| i) The GP Practice | 5 |
| ii) Sexual Health Services | 7 |
| iii) Post-natal Care | 8 |
| iv) Mental Health Services | 9 |
| Theme 3: Communication | 9 |
| i) Primary Care | 10 |
| ii) Maternity Care | 11 |
| iii) Individual Hospitals | 12 |
| iv) Regional Issues – Health Boards and Local Authorities | 12 |
| v) Welsh Government – Shielding Letters | 13 |
| Theme 4: Health-related concerns or fears coming out of the Covid-19 crisis | 15 |
| i) Recommencing Hospital-based Care | 15 |
| ii) Guidance on Health Services | 15 |
| iii) The Impact of Delayed Healthcare on Women | 16 |
| iv) Improving Women's Healthcare Services Going Forward | 18 |
| v) Future prospects for disabled people / with long-term health conditions | 18 |
| vi) Workforce Issues and Solutions | 19 |
| Theme 5: What lessons can Welsh Government and health services learn from the Covid-19 crisis? Women's Health-focused Recommendations | 19 |

1) The impact of cancelled hospital appointments or procedures

i) Cancelled hospital appointments / procedures

Sadly, as is quite typical for gynaecological conditions in Wales, many of our members had already waited years for their operations and / or experienced several cancellations before lockdown. Some spoke of their utter devastation at the decision to cancel what are deemed 'non-urgent' surgeries having finally found themselves at the top of a waiting list or having fought long and hard to be referred to a specialist after several ineffective procedures locally. For these women, the term 'non-urgent' hugely underplays the impact severe chronic pain, organ dysfunction, and, in some instances, infertility has on their lives.

Women spoke of having major surgery, ie hysterectomy, prior to lockdown with no follow-up or information as to findings or next steps, including whether HRT should be prescribed, as a consequence of cancelled appointments. This has caused a great deal of stress, as well as delayed access to treatments which may be essential for positive outcomes. ***A telephone or online consultation may well have allayed fears and enabled shared decision-making on follow-up treatment / medication.***

Whilst women appreciate the need to re-deploy staff where necessary and the avoidance of risk to both practitioner and patient, those who required in-person interventions have found that their cancellation has resulted in more serious medical issues requiring hospital admission. One member spoke of her mesh-related physiotherapy appointments being cancelled, resulting in her needing more invasive assistance with bowel irrigation or risk an obstruction – a medical emergency. Another member described how her feeding tube is no longer working, meaning she has been without adequate nutrition for some time:

I am fed by a NJ feeding tube (but it's) coiled into my stomach and, as it's classed as elective and all electives have been cancelled, it's been a month since I had a tube feed. They don't want to admit me due to the virus...I wouldn't be deemed worthy of ICU support...I know it can't be helped but it's having a big impact on my mental health as I'm struggling to cope.

Should we experience a second wave of Covid-19, or any further pandemics, there needs to be a much more robust analysis of risk, looking at measures which can be taken to ensure that certain procedures can still take place as part of the prevention agenda.

For those women with 'rare' conditions who have to see specialists in order to access restricted medications, the cancellation of appointments has resulted in an escalation of symptoms, particularly when the GP is not able to fill their

prescriptions. ***This is an administrative issue which should have been easily resolved.*** Instead, women have been left to try to self-manage their conditions without medication, alternative and often less effective medication, or attempt to source their first choice of medication online from avenues whose trustworthiness cannot be guaranteed.

I had to wait 3 months to start new medication...On the day the nurse was booked to come and do the first injection at home I was told not to start it because it put me (at) too high risk if I caught COVID-19. I'm now on a much lower strength steroid medication which I am hoping helps but it's just a temporary solution...I have not been able to speak to my consultant about it even though I have asked...With a severe chronic illness that has required hospital admission at its worst I feel very nervous and worried not being able to go onto the medication I need to get better...I feel like I have no plan and I'm just left in a flare up that could potentially become serious.

Women are more likely to be carers or single mothers; for those whose appointments / procedures / operations have been cancelled, the knock-on effects on both their own health and the well-being of their charges cannot be under-estimated.

ii) **Cancelled screening tests**

Women described only finding out that their mammograms or cervical smears were cancelled by scouring the internet for information. For those who have had previous abnormal results, a family history or even symptoms, this lack of guidance and intervention has caused a great deal of anxiety. For some, including those not sure if their symptoms warrant risking a visit to their GP for investigation, the resulting delay may well have serious long-term health consequences.

iii) **Delayed fertility treatment**

Those women undergoing fertility treatment and close to the age-related cut-off point, the cancellation of services, despite a 2-year extension to the programme, has meant that some women are inevitably going to find that their chances of successful treatment have decreased:

Being a more mature fertility patient has made this all the more challenging, emotionally draining and exhausting, trying to explore every avenue until you repeat the cycle from the beginning in your head.

iv) **Lengthy waiting times**

Women who have already struggled on lengthy waiting lists as a result of diagnostic delay and inadequate local services, and who have already experienced cancelled operations prior to the crisis, are now find their waiting times extended further and their health deteriorating.

Since Christmas I have been having much more severe pain in my pelvis and around my bowel area. I see five different consultants and even before the lockdown it was difficult to contact them and get coordinated care. I'm now in significantly more pain and have no idea how long it will be or even how I now contact them.

One member described how, due to numerous cancelled operations, including now thanks to Covid-19, her ovarian cyst has now grown to such a size that she will no longer be eligible for keyhole surgery but will have to undergo a major open abdominal operation, with all of its incumbent risks, costs, and longer recovery time.

2) Accessing GP / primary care services, including sexual health, post-natal care, and mental health

i) **The GP Practice**

In many instances, women in FTWW's online support group report that their GP's reception team has been polite, friendly, and helpful. One member described how streamlined processes have become at her Cardiff-based practice, with on-the-spot triaging, increased availability of telephone consultations, carefully risk-managed in-person appointments where required, in-house blood testing and call-backs to discuss results. The practice's pragmatic, patient-centred approach also had the GP providing three months of a repeat prescription ordinarily provided monthly, so as to reduce unnecessary calls or trips to the pharmacy.

However, for many others there continue to be a number of difficulties associated with seeing the GP, not least fear of contracting the virus or adding to their workload:

In the last few days I have been unexpectedly bleeding from places I shouldn't be, but am too scared to get checked because I don't want to put pressure on the surgery whilst they try to deal with the pandemic, plus I don't want to risk getting it myself.

In contrast, some patients found themselves unable to book an appointment with their GP, even though reviews or check-ups were an essential part of their on-going care or treatment. Many members expressed frustration at not being able to book or attend what may generally be considered 'routine' appointments rather than 'emergency' ones, even though management of their long-term conditions was dependent upon their seeing the GP for various tests or procedures.

Another member described the problems she has had accessing her medication as a result of a recent move to Wales:

I only signed up with my new GP after learning that I needed to stay indoors, so I did that remotely - this was two weeks before the official lockdown. (The GP) insisted they had to see me to give me my prescriptions, but my specialist from my last place had told me to consider myself high risk, so I had go through online pharmacies to get what I needed.

As discussed earlier, this is where ***a common sense, compassionate approach to decision-making should be at the forefront, enabling flexible, patient-centred care.***

Those who have been able to attend in-person GP / primary care appointments found the systems in place to reduce risk of contracting Covid-19 sensible if sometimes challenging to navigate, particularly long, complicated answer phone messages with numerous options or complex triage systems which may be operated by the reception team. For some, the latter gave rise to concerns about having to share confidential information, whilst the former could potentially create significant barriers to access for those with learning disabilities or other cognitive and mental health issues.

Whilst in England, it is commonplace for GP practices to have a patient experience / advisory group who can be consulted in real-time to ensure that reasonable adjustments to policy and practice are considered, this isn't necessarily the case in Wales. ***Going forward, we would recommend that groups of this nature be put in place to serve NHS Wales, local health boards, and primary care hubs, ensuring that the requirements of the Equality Act 2010 are considered by those with lived expertise.*** These groups need not be unnecessarily bureaucratic but an incredibly useful and immediately responsive resource.

Another consequence of the reluctance to see patients in-person, and the Covid-19-related pressures on local laboratories, has been the increasingly protracted

nature of diagnostic processes. For our respondents, this has resulted in both escalating anxiety and worsening of symptoms.

One FTWW member reported how it had taken over a fortnight for a urinary tract infection to be formally diagnosed and subsequent difficulties getting an in-person GP appointment to deal with the cause meant that she was forced to access emergency out of hours care to have her suprapubic catheter changed. Despite this history, she is still finding it difficult to access the necessary preventative care at her GP practice:

I rang my GP surgery about my upcoming change of suprapubic catheter, and whether it would still be done by the practice nurse, and the reply was, 'we are not dealing with any routine procedures or blood tests'...Without this, (I am) more prone to urinary tract infections, kidney infections, stones, and urosepsis...I have already had to diagnose and treat a UTI at home as there was no response from 111...Having been in hospital with urosepsis recently I had no choice.

Welsh Government has committed itself to prudent healthcare principles, one of which is providing patients with the tools to manage their own health as far as is possible. Those working in primary care similarly need access to these tools, so that they can support and guide patients appropriately.

Many of our members have complex, chronic health conditions with multifarious and interacting symptoms – the issue they continually report to us is the systemic barriers to being seen 'holistically'. NHS specialists will invariably focus on one issue or part of the body in isolation and, consequently, both waiting times and communications between each department can both protracted and fractured. Additionally, patients don't always wish to rely solely on pharmacological interventions.

As we emerge from this crisis, with both pressures on services and patients themselves experiencing additional health needs, Welsh Government should consider exploring how every primary care centre, GP practice, or 'hub' could have access to a holistic practitioner who is able to provide patients with the skills to practise non-pharmacological interventions such as reflexology and aromatherapy, supporting well-being and going some way to enable effective self-care.

ii) **Sexual Health Services**

Both during and beyond this crisis, women have repeatedly told us how hard it is to find information about how and where to access local sexual health services. During the crisis, as headlines about the cancellation of 'all routine healthcare

appointments' have taken centre-stage, it's been largely assumed (in some but not all cases erroneously) that sexual health services will be amongst them.

Generally, there has been a lack of well-publicised information on the topic, perhaps because sexual health is not seen as priority or because it's not part of 'polite' public discourse. Whatever the reasoning, it has left many women in Wales struggling with a range of issues, not just around accessing routine contraception but also how to deal with severe reactions to it including, in some instances, escalating mental health issues involving self-harm and suicidal ideation.

I have desperately wanted my Mirena (coil) removed, as I know it is responsible for my cystic acne and mental health decline...My GP couldn't find the strings of my coil when she tried removing it pre-lockdown. My ultrasound has therefore been cancelled, with no clue on when it will be scheduled, simply 'once this is all over, we'll reschedule'. My main reason for wanting it out is mental health issues...Anxiety, barely functioning some days/weeks, I'd started self harming and had a genuine desire to kill myself, and had nearly tried to...I find it shocking that I'm left with (the coil) in place for god knows how much longer, when I've made it so expressly clear that I want it out as I'm worried I'll actually go through with killing myself.

Assumptions that problems of this nature are just routine and can be simply 'left' until normal service has resumed can have disastrous consequences for those women impacted. Indeed, the problems associated with a tendency to minimise, normalise, or outright dismiss women's symptoms isn't limited to lock-down but compounded by it. It's vital that healthcare professionals listen and take seriously those women reporting reactions / situations like this, irrespective of how 'rare' or 'unusual' it may be considered.

In all clinical settings, women in FTWW's support group tell us that their reporting of symptoms is regularly downplayed, which suggests that **tackling bias should be a key part of training for those working in the public sector, particularly within health and social care where outcomes are very much dependent upon the decisions and interventions of personnel. We would recommend that, coming out of this crisis, patient involvement in the delivery of training and assessment of all healthcare professionals in Wales is a mandatory component of any curriculum.**

iii) Post-natal care

Members of FTWW who are pregnant and expecting their babies' arrival during lockdown continued to be concerned about the provision of post-natal care, including access to in-person check-ups of both mother and baby.

I've had to attend all my appointments at the clinic which has been a bit of a struggle combined with stitches and sleepless nights - I don't know what I'd do if I couldn't drive! There will be no health visitor contact beyond a phone call. To be honest, I'm dreading being discharged from midwife care as it's the only support we're getting and things are so isolating at the moment that it will feel like your only support is severed and you're very much in your own.

Peri-natal mental healthcare is another significant issue during and beyond this crisis. Wales continues to have no specialist mother and baby mental health beds with one of the usual alternatives being support and interventions provided in the home, enabling mother and baby to stay together. Given that these options will likely be unavailable, or severely limited, during lockdown, FTWW is concerned about the long-term consequences for those affected.

Whilst FTWW recognises Welsh Government's commitment to trial a specialist mother and baby mental health unit (of 6 beds) in Swansea Bay health board, this is not sufficient or accessible to those outside of south Wales. It is essential that services of this nature are equitable across the country.

iv) **Mental health services**

The provision of primary care-based mental health services is historically patchy across Wales. However, it is with dismay that FTWW learned that some of its North Wales members, under the care of Betsi Cadwaladr health board, had received letters informing them that they had been discharged from services and to ask their GP to re-refer them when the Covid-19 crisis is resolved.

At a time when patients' mental health will be being further compromised by lockdown and when it is more difficult to challenge any such decision as personnel cannot be easily contacted, this is wholly unacceptable and potentially harmful. Undoubtedly, there will be patients experiencing mental health crises as a consequence of these letters. ***We look forward to seeing Welsh Government taking a lead in ensuring that no North Wales patient will be unduly affected by such a policy. We recommend that all patients affected are reinstated on their primary care / community mental health team's list and issued with letters of apology and reassurance as a matter of urgency.***

3) **Communication**

Women in FTWW's online forum have reported a number of issues around communication, both at a local and national level.

i) **Primary care**

Locally and at primary care level, patients experiencing health issues unrelated to Covid-19 reported being uncertain about who to contact or where to go to seek medical assistance. Respondents report feeling that they couldn't go to the GP, both because they were afraid of contracting the virus but also because they believed that they wouldn't be welcomed and / or that their GPs were overstretched with Covid-19-related issues.

I have been poorly while in lockdown and felt I couldn't go to the GP. Not enough info about how the GP practice was working.

The vast majority of our respondents echoed the need for easy-read information made easily accessible to them about how their local practices were working at this time, including risk management strategies. ***Whilst members appreciate that many on-the-ground decisions will be made independently, by each individual practice, general guidance around accessing GP services at this time would have been helpful from Welsh Government.***

Inevitably perhaps, as both personnel and laboratories have been re-deployed, the speed of communicating non-Covid test results to patients has been affected; similarly, follow-up letters and other forms of documentation have been slow to reach their destinations. Whilst understood by patients, this has nevertheless had some impact on mental health, including anxiety levels and the time(s) taken to commence treatment.

Patients with specific communication needs have found this period particularly challenging, including some autistic patients. It has never been clearer that, ***coming out of the crisis, more training is required for those delivering health and social care services, and that it be designed and delivered by those with lived experience of the issues at hand.***

One of our members, an autistic woman for whom, typically, a formal diagnosis has taken decades, described how one of her main issues was communicating effectively:

If I go to my GP (or any other professional for that matter) and ask for help dealing with my emotions and end up having a meltdown, I should not be sanctioned for that -- the idea that I have to manage to remain calm at all times no matter what when I have specifically said that this is something I need help with because I am struggling to do it on my own puts me in this catch 22 bind where I just end up being the loser all the time.

Unfortunately, for this particular respondent, a lack of appreciation of her specific communication needs has resulted in her being discharged at a time when she most needs support. The local autism team has been similarly unable to provide formal support whilst lockdown continues.

Autistic patients, patients with mental health issues, and learning-disabled patients have found many of their self-help activities (such as in-person community groups) severely curtailed during this time, and many are now very isolated and unable to communicate their difficulties through the limited mechanisms currently available. ***This is where adequate PPE becomes absolutely vital for those outreach services which may not be statutory but provide an essential lifeline for otherwise marginalised communities.***

ii) Maternity care

Provision has been patchy across Wales, with different health boards having various approaches. Respondents described how communication around birth arrangements was lacking, particularly with regards to c-sections and the impact of Covid-19. Respondents felt that like they were being batted between obstetrics and midwifery, with a lack of consistent messaging between the two.

I've not found the communication re birth arrangements very good at all and have found the obstetrics bating me to the midwife and then midwife saying, 'oh you didn't need to see me if you were there last week'. It's felt like the message has been come to appointments, but the reality is we've been made to feel like an inconvenience.

One respondent, with a history of recurrent miscarriages, felt that her case for additional support wasn't treated as a legitimate clinical need. Clearly, as FTWW's campaigning has shown, ***specialised care for those women experiencing recurrent miscarriage is lacking across Wales; the Covid-19 crisis has highlighted the urgent need for clear pathways for these patients.***

iii) Individual Hospitals

There have been huge variations in how hospital services are working, not just across Wales but within health boards and individual hospital departments also. Whilst some individual consultants have adopted alternative ways of working, including undertaking telephone appointments, or using video-conferencing, others haven't. At the very least, this has resulted in confusion for patients about what to expect from their providers; at worst, there are patients experiencing

serious exacerbations of existing health conditions with little to no support or advice on what to do.

iv) Regional issues – health boards and local authorities

FTWW has long expressed concerns to Welsh Government around health boards' autonomy to decide upon service-development and delivery.

As a Wales-wide, patient-led, women's health organisation, we have seen how this strategy has resulted in inequality and harm, with some women able to access specialist health services locally whilst others, to whom such services are not available within their health board, having to fight for years to access them. Unfortunately, during the Covid-19 crisis, we have seen this replicated with regards to emergency admissions, cancer treatment / operations, scans and other elective procedures.

There's a lack strong guidance from Welsh Government...Health boards seem to do their own thing...The system just seems more and more unfair all of the time.

It isn't just patients reporting mixed and confusing messages around which services are continuing and in what manner but also clinicians. There is a worrying lack of uniformity of approach between the health boards, meaning that patients are left both confused and, in some cases, severely unwell.

One cancer patient was informed by her consultant that a 'Welsh Government directive' meant that she couldn't have the cancerous portion of her bowel removed as planned. Another consultant in a different health board was unaware of any such directive. What are patients to make of this? It is vital that there is transparency and consistency across the country, so that all patients, irrespective of location, receive the same communications and high-quality care, and so that clinicians themselves are confident in delivering it.

Unfortunately, the Covid-19 crisis has seen citizens experiencing problems with a lack of uniformity in approach from their local authorities as well as their health boards. Under normal circumstances, Welsh Government's decision to give local authorities the power to deliver services 'according to local population needs' has some merit. However, there is limited transparency around how or by whom these needs are assessed and what recourse exists if the citizen disagrees with the local offer.

During lockdown, the strategy of local decision-making has resulted in inequality and confusion for residents, with some local authorities taking measures or providing services whilst others haven't, or much later on. This has included how far / to what extent to pause measures under the Social Services and Well-being Act, impacting on the care available to disabled people, or the delivery of free school meal provision which has left some people reliant upon food banks or accruing debts.

Both local authorities and health boards should ensure that provision of emergency measures / services are clearly and consistently communicated to residents, with Welsh Government oversight to ensure parity and clarity. Residents across Wales should be provided with an easily accessible, uniform mechanism to raise concerns and have them resolved. At times of crisis, Welsh Government should take a much stronger steer of local activities to mitigate risks to those most vulnerable members of our communities.

v) Welsh Government - Shielding Letters

Although access to information is now improving, shielding letters and vulnerability lists have been mired in confusion and disparity. Those issues we, and other organisations, have raised in this regard have not been adequately addressed by Welsh Government. There is a general consensus on the part of FTWW's members that Welsh Government was weeks behind the UK Government in assessing need and issuing advice, to the detriment of those in need.

Welsh Government's original calculations regarding those needing to shield has proven to be a gross under-estimate, with almost double the originally quoted number now in receipt of shielding letters. Many have only received theirs in the last few weeks. Given that we are now more than 2 months into lockdown, this is unacceptable, with countless patients' well-being badly affected as a result. Many of FTWW's most vulnerable and unwell members have been forced to put their health at risk during this period. Others have taken it upon themselves to self-isolate, despite not being eligible for any support or assistance, again risking their health and well-being as a consequence.

I have trouble breathing because (I have) thoracic and liver endometriosis. This was due to be operated on in May 2020 but I'm guessing now as I am not an urgent case I will be waiting much longer. I also had pneumonia and pleurisy at Xmas and therefore should be shielding. However, when I spoke to a GP (I was unable for two weeks to speak to the one I normally see) I was told I I wasn't in the 'at risk' category. So very confusing...

In our first report, we compared the system being operated in Wales to that of England and advised that we should follow suit with some form of self-registration. This hasn't happened, with Welsh Government relying on GPs to add eligible patients to the shielding list. Unfortunately, many GPs in Wales remain unaware that they can do this and so patients here continue to be unable to access the support available to their English counterparts.

Supermarket deliveries or priority shopping slots are key concessions unavailable to those without a shielding letter. When contacted, supermarkets will advise people to register on the government's list – only for people to discover that this self-registration mechanism is only open to those living in England. There is no recourse or point of contact for those living in Wales. Disabled people with special dietary needs have been particularly hard-hit by a lack of consideration on the part of both supermarkets and local authorities; a self-registration system for those shielding would have gone some way to prevent this.

Most impacting though is access to the few safe foods I can eat and products I can use, what with there being supply issues of almost everything. It's been a huge cause of stress, as to eat unsafe things means I'm pretty ill (or rather, even more ill than usual).

Further, Welsh Government was incredibly slow to disseminate information regarding third sector organisations or volunteer bodies able to assist vulnerable people. FTWW only received this communication at the end of May which, 2 months into the crisis, was far too late to prevent the inevitable suffering that some individuals will have experienced.

For those women with rare illnesses and / or for whom diagnosis is delayed, information has been extremely limited, leaving those most vulnerable and unwell of our members struggling to find any sort of assistance from statutory services. Whilst respondents whose circumstances fall into this category understand the difficulties in issuing medical advice, given the current lack of knowledge on how the virus will interact with certain health conditions / medications, the lack of general guidance and accessible support for those in need has been glaringly absent. ***At the very least, a national helpline for those confused about their eligibility and next steps, would have been useful.***

All of those who are shielding feel that they are being left out of Welsh Government's 'roadmap' to post-Covid living and worry that, once again, as people living with illness, they are being marginalised and 'disabled'. ***It is absolutely vital that the experiences and needs of those that are shielding are sought, heard, and play a central role in every new and emerging policy decision.***

4) Health-related concerns or fears coming out of the Covid-19 crisis

As the pandemic has continued, there does seem to be more public awareness across the UK that strategies to deal with the crisis differ in each of the devolved nations – certainly in terms of travel and social distancing. Where health is concerned, however, there are still key issues which require further clarity and communication: one of these is when and where ‘non-urgent’ hospital procedures will recommence.

i) Recommencing Hospital-Based Care

As England begins to lift lockdown, there have been England-specific messages communicated to the UK-wide public around hospitals re-opening and operations re-starting. Understandably, Wales-based patients have come to us, asking if the same applies in Wales and, if not, when will they start. The issue has been compounded for those women living in North and Mid-Wales who regularly access services in England.

Whilst it seems reasonable that they be allowed to travel into England for healthcare, there are added complexities around follow-up appointments which might, ordinarily, take place locally. As an organisation which frequently liaises between NHS Wales / local health boards and our patient community, the lack of any sort of clarity around these issues has been problematic.

(As a north Wales patient), my concern is that I was due to go for my operation (in England) in first week of May. Since then I've not heard a thing... I'm worried that once all this is over I will just be on a long list to wait again when I'm already really struggling day to day with my symptoms worsening...I'm so anxious and emotional and feel like I've fought so hard to get there and was SO close to having the treatment I needed.

ii) Guidance on Health Services

FTWW absolutely appreciates the complexity of the situation around health (and social care) service delivery, aside from the direct impact of Covid-19. However, we are most concerned that the development of health-related guidance is not at the top of Welsh Government's list of priorities, as per page 17 of Welsh Government's roadmap to *Unlocking our society and economy: continuing the conversation*. Welsh Government states that, 'In time, we will consider issuing further guidance in relation to health services and social care'. We would argue that, given the issues explored in this paper, some element of guidance to patients experiencing problems now is essential.

There will undoubtedly be long-term issues to consider further as the Covid-19 situation evolves but there are also immediate circumstances which are rapidly

escalating into health emergencies unrelated to Covid-19 and which need addressing as a matter of urgency. ***With the prevention agenda a key strategic commitment for Welsh Government, it is very important that those most pressing health-related issues are considered, guidance developed, and public messages disseminated now. It is vital that those living with long-standing health issues are included in these conversations so that their specific needs can be met.*** In the same way, as the original end date for the 12-week shielding requirement draws closer, it is increasingly important that those people affected are also included in these discussions.

Currently, women in FTWW who are living with chronic / recurrent – and worsening – health conditions tell us that they feel as though they are ‘disposable’, not least because there has been little to no mention of how they, including those who are vulnerable or shielding, will be factored-into the lifting of lockdown.

In regard to coming out of the crisis, I'm really worried that there are people out there with the virus without symptoms...I can't see how we can be safe without a vaccine in place.

iii) **The impact of delayed healthcare on women**

Many of our members are incredibly worried about how long they will now have to wait for essential surgery. For those patients who had already waited a considerable length of time and, in some cases, experienced several cancellations, there is now a very real fear that they will never be able to access the treatment they need should pressures on the NHS in Wales result in reprioritisation of need and reallocation of monies.

I'm concerned (about) how long we are going to be put back as far as waiting times are concerned...I was on an urgent list and it took 6 months to have my appointment after it was cancelled twice previously...What services will be cut due to lack of funding?

Endometriosis is a prime example of the issues facing women as we emerge from this crisis. A chronic condition affecting the same number as diabetes with only one specialist facility in Wales set up to manage all eligible patients in south Wales, Cardiff endometriosis centre was already under immense pressure. They are now reporting that waiting times for those women on their list for advanced / severe disease (ie with bowel, bladder, kidney involvement, as well as extreme pain) will be in excess of 18 months once non-cancer operations resume.

As Welsh Government begins to explore long-term solutions to health-related problems caused or exacerbated by this pandemic, changes in how complex tertiary care is funded need to be enacted as soon as possible. Monies need to follow patients into Cardiff's endometriosis centre, ensuring that its 3 specialists can focus on expediting all patients and reducing back-log as soon as it is safe to do so. Considering funding of referrals into England's neighbouring centres would be an optional extra once the funding for Cardiff is resolved.

It is also important to highlight that whilst recommencing the work of fertility centres is laudable, for endometriosis patients whose disease has not been treated by a specialist in the first instance, this treatment may well prove ineffective. These patients, particularly those whose age is a factor, should be amongst those considered for expedited endometriosis excision with a BSGE-accredited specialist multi-disciplinary team before embarking on their fertility treatment.

Endometriosis is just one condition where women's healthcare has historically been subject to cultural prejudices resulting in delayed or erroneous diagnoses, normalisation, and lack of investment. FTWW is concerned that any possible redistribution of funds and provision away from women's health would be hugely damaging and a retrograde step for women's equality in Wales.

Welsh Government must not allow women to experience a disproportionately negative impact on their healthcare, especially as women tend to be our nation's carers and essential workers. One key means to avoid this is to re-examine strategy coming out of Covid-19 through a feminist lens, with the intention to be a 'feminist government' at the forefront.

iv) Improving women's healthcare experiences going forward

In section 3.i we talked of how communicating one's needs can be difficult for certain communities. It's important to realise that this is an issue for many women when they enter healthcare settings. Certainly, many of the women in FTWW report having significant issues communicating with their healthcare providers. Partly, this is to do with the culturally entrenched power differential between medic and patient, with women describing feelings of disempowerment when it comes to having their symptoms taken seriously and treatment plans agreed.

I mean, I really just am at the point where I am done with asking for help because 2+ years on I have got nowhere and it has got to the point where asking for help has become triggering and the process is so upsetting to me.

The present status quo leaves many patients totally disengaged from their own healthcare, making achieving positive outcomes far more difficult. Welsh Government's focus on prudence requires making genuine, shared decision-making a reality, where women don't feel dismissed or strong-armed into accepting inappropriate care. Indeed, **women can become active, respected players in their own health management if we revisit the way we train medical professionals coming out of this crisis. Patient involvement in the design, delivery, and evaluation of the medical curriculum, as well as continuing professional development is one fundamental way to ensure unconscious biases are addressed, patient outcomes improved, and costs reduced.**

v) Future prospects for disabled people / those living with long-term health conditions

There seems little doubt that Covid-19 will have significantly impacted on people's future employment, with many businesses closing and jobs being lost. Inevitably, there will be increased competition for positions once lockdown restrictions are eased and 'normal life' resumes. For FTWW's members, many of whom are disabled, there are concerns that this situation will negatively impact on them more than most.

In an economy where businesses will potentially have loans to repay and other increased overheads, will employers be willing to take on disabled people, knowing that they may have to make reasonable adjustments, or will it be easier just to take on those without any additional needs? At a time when we've seen just how easy it is to work remotely and make those accommodations which so many disabled people have long requested (and often been refused), **it would be a travesty to now overlook the many and varied skills, experiences, and contributions disabled people can make to the workplace, as we revert back to typical ways of thinking and working. Welsh Government needs to begin exploring mechanisms to ensure this doesn't happen, starting now.**

I worry about everyone forgetting what (lockdown) is like, and how those of us who were already housebound will continue to live like this. (Covid-19) has given able-bodied people an insight into our lives but I fear that will quickly be forgotten...All the measures that have been put in place, from simply checking in with one another, to suggestions on how to fill time, to online contact, to more official services, to employee adjustments, have all really benefited disabled folk and actually made our lives a bit better...Once this is all over, I fear it will all just be quickly dropped and our lives will go back to being that bit harder.

vi) Workforce issues and solutions

Covid-19 has made us all more aware of how those providing health and social care services, whether they are in the public, private, or voluntary/third sector, have been on the front-line of this crisis, demonstrating that they provide some of the most essential services in our society. It is time for a cultural re-evaluation of this type of work, indeed what is often considered 'women's work', whether that be in healthcare, social services, teaching, or in the voluntary/third sector, providing care and support to others.

Welsh Government needs to think outside of the box, and proactively, to ensure that we incentivise our own young people to 'train and remain' in Wales, becoming the next generation of health and social care workers. A system where Government covers both training and living expenses in exchange for individuals' contractual commitment to work within that sector and 'close to home' for a period of time would ensure that Wales reaps the rewards of its investment in future health and social care workers and also boost the local economy.

Representatives of the service sectors should be formally invited into schools across Wales to let our future generations know that these are professions of worth, and that entrants can both earn a good living from them and be valued as individuals. We need to change the narrative around health and social care, so that ambitious students go into these sectors knowing that they will be both resourced and fulfilled.

5) What lessons can Welsh Government and health services learn from the Covid-19 crisis? Women's Health-focused Recommendations:

- 1 Welsh Government is right to be conducting this inquiry. However, those of us 'on the ground' need to feel as though we are a real part of the conversation and solution-finding. Heeding the feedback from individuals and communities most affected is key, so that appropriate measures are ready to go should we have to lockdown again**
- 2 The Covid-19 crisis has shown us that healthcare services can and should be delivered more flexibly and according to patient need. It is very important to offer patients choice and not foist particular methodologies on them. A stronger line**

over the Public Services Equality Duty, the need for which doesn't cease during a pandemic, is vital. Health service-providers must be open to reasonable adjustments, with easily accessible mechanisms in place for patients to make their needs known. It must be appreciated that not every requirement will be one that can be met with physical environmental changes – some find that it is others' attitudes which are most disabling. This can include a failure to recognise the significance of invisible impairments or not being tolerant of difficulties communicating

- 3 Service providers need to work with a range of disability advocates to have a fuller appreciation of the needs of the community. Similarly, where clinical interventions are required, in some instances, patients can be entrusted to manage their own care if given the necessary support in the first instance. For example, patients requiring regular injections may not need to visit the GP or hospital each time, if they were sufficiently skilled and confident to do their own. Ultimately, open discussion and shared decision-making are key to providing best, most appropriate care. We would recommend that patient advisory groups be put in place to serve NHS Wales, local health boards, and primary care hubs, ensuring that the requirements of the Equality Act 2010 are considered by those with lived expertise**
- 4 Should we experience a second wave of Covid-19, or any further pandemics, there needs to be a much more robust analysis of risk, looking at measures which can be taken to ensure that certain clinical interventions can still take place as part of the prevention agenda. Welsh Government might consider designating certain hospitals / centres purely for Covid-19 patients, in order to both contain outbreaks and enable other clinical settings to continue to provide routine healthcare services. This type of clearly delineated provision may have helped to avert a non-Covid-19 healthcare crisis coming out of lockdown. Outside of institutional environments, adequate PPE is absolutely vital for those outreach services which may not be statutory but provide an essential lifeline for otherwise marginalised communities**
- 5 As we emerge from this crisis, with both pressures on services and patients themselves experiencing additional health needs, Welsh Government should consider exploring how every primary care centre, GP practice, or 'hub' could have access to a holistic practitioner who is able to provide patients with the skills to practise non-pharmacological interventions such as reflexology and aromatherapy, supporting well-being and going some way to enable effective self-care.**
- 6 Tackling bias should be a key part of training for those working in the public sector, particularly within health and social care where outcomes are very much dependent upon the decisions and interventions of personnel. We would recommend that, coming out of this crisis, patient involvement in the design and delivery of training and assessment of all healthcare professionals in Wales is a**

mandatory component of any curriculum.

For women's health in particular, the emergence from lockdown should be viewed as an opportunity to re-examine how decisions are made and strategy developed. When it comes to healthcare, FTWW is calling for cultural change, starting with recognition of the impact unconscious bias and gender stereotypes can have on women's health-related experiences, as well as (the under) investment in research and service provision. Previously, we have highlighted some key statistics which underline the problems women face as a consequence of diagnostic delay for a whole host of different health conditions; it is vital that any 'new normal' takes women's reporting of symptoms seriously, invests appropriately, and ensures that provision for women's health is not deprioritised in the midst of increased demand on NHS services. Patient outcomes will improve, and costs to the public purse will be reduced as a result

- 7 Coming out of the Covid-19 crisis, menstrual well-being needs to become a mandatory part of the new school curriculum, which would go a long way to overcoming taboos and prejudices and reducing diagnostic delay. Our future healthcare professionals are in those classrooms, so work we do now to improve understanding of the societal barriers girls and women face to accessing best care results in improved experiences for future generations**
- 8 We look forward to seeing Welsh Government taking a lead in ensuring that no North Wales patient will be unduly affected by the decision to remove existing mental health patients from primary care waiting lists. We recommend that all patients affected are reinstated on their primary care / community mental health team's list and issued with letters of apology and reassurance as a matter of urgency. This is just one example of why it is so important that Welsh Government has a much stronger presence and guiding hand when it comes to local service delivery by health boards and local authorities. The Covid-19 crisis has clearly demonstrated that allowing local bodies to decide for themselves on what they deliver, when, and to whom can result in confusion, inequality, and potential harm**
- 9 In healthcare, one of Welsh Government's responsibilities should be to ensure that all patients in need across Wales are offered the same level of assistance from their healthcare professionals, and that these plans are clearly communicated to all parties, ensuring equality of service and reducing mixed messaging. Both local authorities and health boards should ensure that provision of emergency measures / services are clearly and consistently communicated to residents, with Welsh Government oversight to ensure parity and clarity. Residents across Wales should be provided with an easily accessible, uniform mechanism to raise concerns and have them resolved. At times of crisis, Welsh Government should take a much stronger steer of local activities to mitigate risks to those most vulnerable members of our communities**

- 10** When it comes to primary care, whilst it's appreciated that many on-the-ground decisions will be made independently, by individual GP practices, general guidance around accessing GP services at this time would have been helpful from Welsh Government. Speedier, more efficient, clearer communication to vulnerable patients, including letters to those who have complex health conditions but may not be deemed within the shielding group; helplines; mechanisms which enable people to be pro-active themselves, such as registering themselves on vulnerability lists, would have saved time and prevented unnecessary confusion and hardship
- 11** Having the right to live and act independently is something which Welsh Government has been keen to see embedded for disabled people; this needs to be extended into the delivery of health services across Wales. Welsh Government needs to look urgently at self-referral systems, both into social prescribing activities and statutory services (whether that's secondary / tertiary medical care or social services). The only points of access currently are via the GP, primary care, or A&E, all of which, during this pandemic, have proved to have serious limitations as a result of regular access being 'suspended'
- 12** We would ask that Welsh Government and health boards pay attention to the nuances of 'prevention' in women's health. Whilst prevention of actual illness / health condition, ie endometriosis or menopause may not be possible, there is still much that a preventative approach can offer. Central to this would be improving symptom recognition by the public at large, enhancing training of healthcare professionals to focus on reducing unconscious bias and facilitating shared decision-making, and the development of consistent referral pathways so that women can access specialised care in a timely fashion. All of this prevents escalation of issues in terms of both illness and wider socio-economic impacts. Covid-19 has demonstrated very clearly that service-providers at all levels are so focused on fighting fires that we don't look at mechanisms to prevent future harms.
- 13** Welsh Government could do more to actively encourage and facilitate patient involvement in health service design and delivery as per the Social Services and Well-being Act. FTWW has been working with the health board in North Wales to establish an effective model of co-production in women's services which we would like support to replicate across Wales
- 14** Knowledge of referral pathways amongst healthcare professionals must be improved to facilitate prompt, seamless care, consistent across Wales. A regularly maintained NHS Wales online directory, making clear to patients and clinicians alike the location (including in England) of consultants with special interests and tertiary / specialist centres to whom patients can be referred would speed-up

access to best care, reduce inefficiency and waste, and improve long-term outcomes

- 15 Health boards and departments should be regularly audited to make sure they are utilising appropriate referral pathways. Reaching out to patients for their experiences should be a key part of any such analysis. Where such pathways or specialist tertiary services don't exist, NHS Wales needs to target its investment accordingly, including more specialist provision for endometriosis, dedicated menopause clinics in every health board, and specialised care for those women experiencing recurrent miscarriage
- 16 As Welsh Government begins to explore long-term solutions to health-related problems caused or exacerbated by this pandemic, changes in how complex tertiary care is funded need to be enacted as soon as possible. Monies need to follow patients into Cardiff's endometriosis centre, ensuring that its 3 specialists can focus on expediting all patients and reducing back-log as soon as it is safe to do so. Considering funding of referrals into England's neighbouring centres would be an optional extra once the funding for Cardiff is resolved
- 17 It's essential that Welsh Government recognises the vital role of Public Health Wales, not only in terms of managing any future pandemics but also in improving women's experiences both during and beyond them. Conversations are multiple and varied but should include the impact of cancelled screening appointments, menopause, menstrual health, cardiovascular disease in women, and an expansion of the narrative around adverse childhood experiences to encompass the mental and physical health of the women giving birth and looking after those children
- 18 Information-sharing amongst healthcare professionals, departments, and health boards needs to be urgently improved. When 'normal service' resumes and face-to-face interventions recommence, we must make every effort to move away from the reliance on handwritten notes and drawings to elucidate what treatments patients have undergone. Historically, this has resulted in delays, miscommunication, and ineffective, sometimes repeated, interventions. Investment in the technology throughout Wales to make efficient and consistent communication, including the sharing of surgical pictures, a reality is essential. This extends to patients being able to access to their own medical records online, an essential step in enabling self-management of health and care
- 19 As we emerge from Covid-19 lockdown, it has never been more important that the experiences and needs of those that are shielding, vulnerable and / or living with health issues are sought, heard, and play a central role in every new and emerging policy decision, so that their specific needs can be met. Both now and into the future, Welsh Government, NHS Wales, and local health boards need to work with patients to co-produce and properly resource health services going forward rather

than making assumptions about need, resulting in inefficiency and waste. The fear for the many women living with ill health is that waiting lists for our scarce specialist services will increase dramatically because, historically, funds have not been directed at ensuring the necessary provision. Welsh Government and local health boards need to be open to listening to patients / patient groups, working collaboratively, and co-producing radical solutions

- 20 Welsh Government must not allow women to experience a disproportionately negative impact on their healthcare following on from this pandemic, especially as women tend to be our nation's carers and essential workers. One key means to avoid this is to re-examine strategy coming out of Covid-19 through a feminist and intersectional lens, with the intention to be a 'feminist government' at the forefront
- 21 Across the UK and during this pandemic, women, especially disabled women, have been largely absent from the decision-making table. Whilst Wales sees women better represented at a government level, there is still a worrying lack of representation at a regional level or from those with protected characteristics. As a consequence, those issues affecting these communities will remain largely unheard, despite the disproportionate impact of Covid-19 upon them both in the immediate and long-term. Going forward, it is vital that these voices are not just heard but that they play an integral role in service design, implementation, and evaluation. Covid-19 should be seen as an opportunity to make this happen
- 22 Welsh Government needs to actively champion the many and varied skills, experiences, and contributions disabled people can make to the workplace, as has been seen throughout this crisis, collaborating with communities to ensure that any 'new normal' doesn't exclude disabled people / people living with long-term health conditions. Welsh Government should consider leading by example in terms of prioritising the lived experience in appointments to its civil service
- 23 When it comes to the future staffing of health and social services in Wales, Welsh Government needs to think outside of the box, and proactively, to ensure that we incentivise our own young people to 'train and remain' in Wales, becoming the next generation of health and social care workers. A system where Government covers both training and living expenses in exchange for individuals' contractual commitment to work within that sector and 'close to home' for a period of time would ensure that Wales both reaps the rewards of its investment and boosts the local economy
- 24 Another very important employment opportunity highlighted by the Covid-19 crisis has been the key role of lived experience advocacy. Going forward, there is a clear need to recognise, utilise and incentivise the lived experience in a professional, paid capacity. Being supported by a health worker, care navigator, or advocate

who is living with the relevant health condition themselves can make a positive difference to patient outcomes whilst also resulting in better / more appropriate access to services and less waste. This may be a role for the third sector – but access to sustainable funding is crucial in enabling them to continue to both support citizens and service providers.

FUNDING