

Written Evidence from This Independent Life [WRH0026]

About Us

This Independent Life is a social impact organisation supporting people to achieve independence in life, regardless of their background. Following a successful career in the healthcare industry, founder Rebekah Lloyd experienced a mental health breakdown, received a diagnosis of depression and anxiety, and a 10 year delayed diagnosis of endometriosis. The resulting negative impact on her career, financial situation, and life overall helped her to uncover the severe unmet needs and intersectionalities of women's health, work and money and she created This Independent Life to help people to rebalance and create equity through support in these 3 core areas of life. This Independent Life facilitates positive change by putting facts, stories, and experience at the heart, including educational and cross-industry collaborations with corporates and educational institutions such as Imperial College London and Schroders, consulting and advising women's health research and startups such as University of Oxford and Perspectum, and hosting innovative community initiatives and events such as a first-of-its kind global patient-led endometriosis conference in 2023 with 45 partners across the healthcare space.

This submission is sent on behalf of the 19 members of our community who responded to our anonymous survey, as well as our wider community. The full source responses are available in the appendix at the end of this document.

We are available to attend oral evidence sessions pertaining to the Inquiry. We would welcome the opportunity to contribute and be involved in the resulting activities and implementation following the Inquiry.

A note on intersectionality and inclusion

The nature of the inquiry and evidence submission excludes large numbers of women. We feel that the wording of the call for evidence implies that women need a diagnosis in order to be able to respond. With the extraordinarily long wait times and general lack of education around women's reproductive health faced in the UK, we feel that this excludes the experiences of women who are still seeking a diagnosis, those who have given up on receiving one and those who have been told they are "too young" or "too old" to have these conditions.

We know, as detailed in the 'Women's Health Strategy for England' (2023) that there are major disparities in women's access to health care. The nature of the inquiry risks the further and continued exclusion of these and other marginalised groups of women and must find effective ways to ensure the meaningful inclusion of otherwise

excluded groups including (but not limited to) women of colour; women who are physically and/or learning disabled; women from traveller communities; asylum seeking women; women who do not speak English as a first language, or who otherwise have low levels of English language proficiency or comprehension and; “younger” and “older” women.

Our Respondents

Amongst our respondents, the most common conditions women were dealing with were endometriosis (44%) and fibroids (33%). Respondents also cited adenomyosis, ‘other reproductive conditions’, Polycystic Ovary Syndrome (PCOS), endometriomas and urinary incontinence. Some respondents will have multiple diagnoses.

It is noteworthy that over 16% of respondents had never, or not yet been able to receive a diagnosis, despite enduring years of disruptive and debilitating symptoms and multiple visits to multiple doctors, A+ E and specialist hospital departments.

Respondents’ anonymous answers to our survey have fully informed and, in many cases, are quoted in our submission of evidence to the Inquiry.

What constitutes healthy periods and reproductive health?

The majority of responses to this question focused on the absence of highly disruptive pain, the length of the bleed during the period (most said 5-7 days) and the heaviness/flow of the bleed and number of sanitary products needed during a 12/24 hour timeframe. A “regular” (28-32 days) cycle was also mentioned frequently.

Respondents highlighted that a healthy period and good reproductive health should not interfere with the ability to live daily life.

“I think a healthy period is one that doesn’t interfere with life. I spend weeks anticipating my period. The number of healthy days I have shrinks to just a few days a month.”

Respondents also noted that in the presence of disease, or other condition, intervention, management techniques and appropriate medical support were needed to be able to manage pain and other symptoms in order to have as healthy a period/menstrual cycle as possible. Wider education on what constitutes a “healthy period and reproductive health” were also raised as key issues.

Most of our respondents felt that their condition/s (diagnosed or not) impacted either their ability to undertake regular tasks including going to work, self-care/personal hygiene and caring responsibilities and/or their relationships (personal and/or at work).

“I often struggle with working due to brain fog caused by inflammation. Pain and body aches often require painkillers such as Codeine. I often am unable to make it to the office and constantly worry I will lose my job due to my condition. It limits my ability to exercise, socialise and have relationships due to either continuous bleeding, exhaustion or painful sex.”

“It has taken a major toll on my body and mental health. It has had an impact on my relationship because all my energy goes to managing pain and trying to push through life and then I have nothing left for anything else.”

“It has had a huge impact on both professional and personal life. I had to quit my job due to severe mental health issues as a result of having to live in chronic pain as my team didn't understand and weren't able/willing to offer the flexibility and support I needed. My relationship with my partner has been very strained at times...”

Many respondents told us that they either don't work, work part-time (when they would like, or need to work full-time) or have had to compromise on their careers and where/when they can work. Some of the community have had to start working for themselves in order to be able to manage their pain, symptoms and mental health, especially where commuting is not an option (e.g. due to pain), or where workplaces are unsupportive. Other members of the community are entirely unable to work.

In summary, healthy periods and reproductive health are defined by the absence of severe and debilitating symptoms, including (but not limited to) heavy bleeding and pain, the effective management of symptoms when they do occur and the ability to lead a life where it is possible to work, maintain relationships and good mental health and undertake other tasks and activities as wished and required.

What are women's experiences of being diagnosed with, undergoing procedures and being treated for gynaecological or urogynaecological conditions?

Diagnosis

The picture around diagnosis is extremely complicated. Only two respondents found getting a diagnosis easy, with the remainder finding diagnosis (if received) took between 3 and up to 20 years, multiple tests, specialists, appointments and, in many cases, varied diets, as well as feelings of dismissal, not being understood, or clinicians having inappropriate or inadequate knowledge, education or training.

Many of our respondents (and women we have spoken to more generally) have not received a diagnosis and continue to face long delays, multiple tests and appointments and a lack of knowledge and understanding from the medical profession. Many of the women we spoke to felt the nature of the inquiry appeared

to dismiss the experiences of those who are still waiting, or who have given up on diagnosis.

“I had been suffering from extreme abdominal pain, excessive bleeding outside of my period. It affected my ability to work, as it was a very regular occurrence and I could hardly move. A conclusion was never reached. I was simply told that I would have to learn to live with my condition. After years I felt I had no option but to give up on the idea of a medical diagnosis.”

Procedures and Treatment

“Despite having a diagnosis I still struggle to get informed opinions and have been left to do my own research to try and ease my symptoms and arm myself with more information to present to doctors so that they will listen to me. Overall it has been one of the hardest and most stressful experiences which continues to wear me down.”

Our respondents have overwhelmingly been offered multiple hormonal treatments, including oral contraceptive pills and various brands of Intra-Uterine Device/coil. The majority have struggled with horrific side effects and been faced with having to try lots of different options, with many never finding the right one.

“I then had the mini pill after my daughter was born and then the Mirena coil which made my PMS symptoms worsen into PMDD.”

“Many many birth controls: pills...Hormonal Suppression DOES NOT help me. I am off of birth control and would rather deal with the pain that comes with natural cycles than hormone suppression.”

“I was put on the combined contraceptive pill as I was told it would “regulate my periods”. I really struggled with the side effects, but continued with it as I really believed it was putting things right. It was only when I started to read up on the pill in more detail, that I realised it was masking a problem and not solving it.”

“I was put on hormones to manage the adenomyosis that gave me suicidal ideation and led to 40 lbs of weight gain.”

A recurrent theme here, again, is feeling dismissed, or misinformed by healthcare professionals.

“No one seemed to know what to do despite it (fibroids ?) affecting 50% of women! One gp told me it only affected black women so I switched to a female gp.”

“ (I was) told my cervix was damaged... When I asked further questions the doctor told me “it didn’t matter” and that the doctor wasn’t sure if the coil had been fitted properly so I had to keep an eye on it in case it came out. I was dismissed despite being in pain and dizzy and clearly distressed.”

“My surgical experience was not good. Apparently there was something not normal but the doctor was unable to come to a conclusion and instead made me feel like I was the problem.”

Our respondents have told us that receiving treatment and undergoing procedures for reproductive health conditions is challenging, complicated and varies massively depending on which healthcare professional women have access to, where they live and whether they have access to private health insurance, or are being treated on the NHS. This demonstrates a clear lack of policy leadership, as well as disparities in healthcare professional knowledge, education, training and understanding.

Helpful, but less widely available treatment

When asked whether there was any kind of treatment or support respondents would have liked, but have not been offered, many said there was.

A number of respondents highlighted pelvic floor physiotherapy, which is available through some NHS Trusts, but is not routinely available. All respondents who have received this, or who are waiting to do so, have said that they had to self-advocate in order to be offered this and that it was routinely offered, even where it was available. One respondent said they wished they had been offered it following surgery, rather than having to search for the treatment themselves.

Respondents further highlighted the need for psychological therapies and specialist mental health care. This appears to be offered in a handful of areas, but should be an offer to all women with reproductive health concerns, as the impact of these diseases on quality of life is huge. The majority of respondents who have received, or are waiting for mental health support have either paid to access this support privately, or been offered generic mental health support, such as CBT, which does not take account of the very specific needs of this group of women.

What disparities exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?

Our response to this question is included in our response to the below question.

What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?

Unequal access to information

All of our respondents felt there was unequal access to information on the range of conditions they are facing. Responses included information on disease and treatment often being “behind paywalls” and the lack of attention paid by healthcare professionals. Most respondents felt they had been dismissed, “gaslit” and not believed by healthcare professionals.

“It feels very hit and miss in terms of whether you’ll see a doctor who will be able to diagnose gynaecological issues.”

“(O)ur health system is full of bias, because medical research has always been based on men, so we don’t understand that women experience things differently, and because women’s pain is dismissed.”

“There is a huge issue with institutional sexism and racism, and how people from different socioeconomic backgrounds are treated. There is not enough education.”

The issues here represent a wide lack of education on women’s reproductive health, both at the individual and healthcare professional level. Members of our community feel that they have to turn to online communities and self-directed education, in order to understand their disease and the options available to them, both when seeking and after receiving a diagnosis. This burden should not be on individual patients and on groups of lived-experience advocates, yet it is.

Discrimination

Many respondents and wider community members feel that they have been discriminated against precisely because they are a woman. Most of our respondents have highlighted that their pain has not been believed, or that they have been expected to live with their pain and other symptoms. With the prevalence of women’s reproductive health conditions so high, it is deeply concerning that women’s pain and experiences are still being dismissed and/or misunderstood.

Some of our respondents also felt discriminated against due to their age. One was told that the best available treatment wasn’t an option for her and had to fight to ensure she received it:

“(T)he fibroid was the size of a melon and I had to have a hysterectomy when I was 36. In the process of getting to the hysterectomy the NICE guidelines said a woman of childbearing age who hasn’t had children wasn’t allowed a hysterectomy.”

Another wasn’t offered the best treatment as she was considered “too young”.

“When I was 16 the doctor refused to put me on oral birth control due to my age. I had a Kyleena coil which was inserted in 2020 however it happened to be one of the most traumatic experiences.”

“(I) suspect my age has [affected my care] (being dismissed as too young for my symptoms to indicate a serious condition).”

Our own data is limited, as most of our respondents identify as white, cis-gender, heterosexual women. We know that women of colour, transgender and non-binary identifying women and those who identify as being “queer” have different experiences and face longer waits with more discrimination and mistreatment than those we have spoken to. We also know that treatment is very difficult to access for

those who are physically and/or learning disabled, travellers, asylum seekers and members of other intersectional and marginalised groups.

Additional to the discrimination faced by younger women, we also know that older women are often dismissed, due to the myth that reproductive health conditions “disappear with the menopause”, which is incorrect.

Healthcare professionals’ knowledge

Our respondents have all drawn attention to instances where they have not been heard, or believed, been told their pain is something all women experience, have been referred to inappropriate specialists, or have been given incorrect information. In many cases, healthcare professionals are acting within the guidelines, or within the scope of their existing knowledge, but women’s health issues are not uncommon, whereas knowledge on them is and guidelines (such as NICE) are outdated and not in line with global best practice.

“My GP has told me that any studying about the disease has to be done off their own backs and in their own time. Statistics about women’s health are horrifying and especially the dismissal of older women or POCs. More understanding is needed during university and women need to be taken more seriously.”

Access to care and waiting lists

We have highlighted above the extremely long waiting times, number of visits to numerous healthcare professionals and departments, tests and scans etc. that women have faced in seeking a diagnosis, but access to care does not often improve with a diagnosis. Even after women are diagnosed with any of the conditions we have already discussed, they are often dismissed, told their symptoms will eventually improve, or are nothing to worry about, or face very long waiting lists for further appointments, surgeries etc.

“I have been trying to see a gynaecologist since February. My appointments have been pushed back 3 times and I am not convinced I will get seen this year.”

“I have been seen once since my laparoscopy in 2022. There is not equal access in the UK and it is primarily due to lack of understanding of women’s health but also being taken seriously by doctors. I am often dismissed despite having an actual diagnosis.”

We also know that when women are under treatment, what they are offered varies greatly and is dependent on where they live and what is available in their area. Treatment options are not uniform across the UK for the same condition and many of our community feel that what you are told or offered may even vary depending on the luck of which doctor you happen to be seen by (even within the same area). This variance is unacceptable. Where you live should not determine your health outcomes.

“It feels very hit and miss in terms of whether you'll see a doctor who will be able to diagnose gynaecological issues.”

“Women are often ignored by the GP and it is put down to 'painful periods' or 'just one of those things' have to really push and be persistent in getting a hospital appointment referral for investigation.”

“I had to wait 6 months to speak to a menopause expert who wasn't even in the local health care trust, because Wiltshire doesn't have one.”

What else does the inquiry need to know, investigate or ask?

Responses all direct quotations from our respondents

“Gynaecological conditions should not be a postcode lottery. That GPs need mandatory education covering the entirety of female gynaecological conditions from birth to death. That women of any age have the right to decide what happens to their reproductive organs, especially if they're confident they don't want children.”

“Where is the money for our research? When will period products be FREE for everyone??”

“No vat on any period products, more education for GPs, more accessibility to fertility diagnostic services.”

“1. Listen to us and don't dismiss us 2. Fund women's health care 3. Provide us with information and support from the beginning.”

“Provide women specific service related to what we experience at different ages eg periods, children, menopause, old age.”

“Educate the public and GPs on the complexity of gynaecological conditions. One of the challenges with gynae issues is that many conditions share similar symptom profiles. Doctors need to be educated on these nuanced. Also, increase education around hormones.”

“Education,(this should include GP's, they need to be able to recognize the symptoms within women and refer appropriately) research and funding. Too many women are suffering with next to know help and support. There is some good work going on, but it does not have fair and equal national coverage.”

“Help to improve timing of diagnosis and support for people; help with access to materials and the correct information; to improve funding to research for women's health.”

“Research - women are not small men. We experience things differently. Our medicine dosages are not always the same. We need to understand why this is, and use it to improve the lives of women.”

“Advocacy - we need to dismantle the biases that exist towards women. Progress has been made, but these biases still very much exist.”

“FUNDING. None of the above can happen without funding. Fund the research, fund the advocacy projects. Stop making women an afterthought and make these things accessible and a part of every day life.”

“Research is essential, I think the core issue is lack of research that leads to poor medical education and lack of solutions (treatments, products, diagnostic tools, etc).”

“Stop waiting for major complications to occur instead Why don't you prevent things from getting worse ie: we should have things like annual check ups so cancer and other diseases can be caught earlier and not when it's gotten too late. Listen to women when they say they are having pain, fatigue and advise them to do things like keep a pain/ symptom diary to best be able to advise on issues. Also don't just dismiss their concerns and say it's normal.”

Our Recommendations and Questions

- This inquiry MUST speak to women with intersectional identities. The written submission of evidence to the inquiry may be how things have always been done but it certainly excludes huge numbers of women, who do not have access to the internet and technology, have low literacy or English language levels and who do not identify or see themselves represented by Parliament.
- This inquiry MUST NOT simply repeat the conclusions reached in the ‘Women’s Health Strategy for England’ (2023) and must, instead, complement that work and enable its progression.
- How is the proposed £25 million for women’s health hubs going to be spent and what tangible difference will this make to women’s health outcomes? With over 33 million women in the UK, this amount totals just 76p per woman. How will this impact women?
- What sustainable plan is being put in place so that women’s health care, hubs or otherwise, don’t get incorporated into an already struggling NHS healthcare system once the current allocated women’s health budget is utilised?
- Beyond women’s health hubs, what is being done to address the state of women’s health within the NHS, and the NHS overall, to overcome arguably the worst situation we’ve since its inception to improve care and support for struggling staff and patients?
- What women’s health economics research is being done to prove and amplify the benefits of a healthy population including all members of the population and help move policy forward to create long lasting change?
- Education and training for health and care professionals is outlined as a priority in the ‘Women’s Health Strategy for England’ (2023), to what extent will those with lived experience be involved in creating and delivering the proposed new curricula? How will the Government ensure that education is rolled out across the board?
- How do the Government plan to improve education for the general public, across different socioeconomic backgrounds, on these women’s health conditions to reduce time to diagnosis and improve prognosis and long term management of conditions?
- What plans do the Government have for improving collaboration across sectors to ensure more joined up working between e.g. research, policy and delivery and to

integrate the innovations emerging across the FemTech sector for improved women's health outcomes?

- What budget is being put towards prioritising and increasing academic research to better understand these women's health conditions, and to support women's health innovation, e.g. startups, to address the lack of available treatment options?
- What are the next steps for implementing the recommendations and findings of both the Inquiry and the 'Women's Health Care Strategy for England'?
- What are the plans to create and incorporate legislation, policy and law to ensure employers have to provide adequate support for women struggling with their health, similar to the recent flexible working bill?
- How will the inquiry and the Government work with the devolved governments to ensure parity across the four nations of the United Kingdom?
- How do the Government plan to ensure women's health care moving forward is patient centred and preventative?

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