

BRISTOL WOMEN'S COMMISSION

Introduction

Key priorities

- 1. Women's reproductive life course

 - 1.1. Young women
 - 1.2. Maternity
 - 1.3. Menopause.....

- 2. Incontinence and pelvic organ prolapse
- 3. Awareness and understanding of women's health issues

 - 3.1. Women not feeling listened to
 - 3.2. Training and research about women's health.....

Additional issues

- 4. Mental health.....

Introduction

Key Priorities

1. Women's reproductive Life Course

Women have as the backdrop to their lives and all other health conditions their normal reproductive life course, including menstruation, birth control, childbirth, breastfeeding, and menopause.

1.1. Young women

Puberty and periods

We hear that many young women of secondary school age feel that they are not supported properly with regards their menstrual health, e.g. they are often not allowed to go to the toilet during lessons. Young women who experience painful and/or heavy periods get little support and have little access to info etc.

Authentic education about how girls' bodies transition through puberty, and the impact of hormones on emotional wellbeing, is not available in appropriate places such as schools. This can lead to disordered eating due to body image issues.

Self-harm

Emergency Department (ED) presentations in Bristol are consistently highest among

females aged 20-24 and second highest among females aged 15-19. The Bristol Self-Harm Surveillance Register reports that 1,831 episodes of self-harm have been recorded amongst students (aged 15 and above) between 2010 and 2018; these episodes account for 12.7 % of attendances. The majority of students were aged <25 years (95%) and were female (75.7%).¹

1.2. Maternity

Around 80% of women will give birth (Davies, 2015) and many women will also experience pregnancy through termination, miscarriage, and stillbirth.

Black, Asian and Minority Ethnic Women

Evidence has long shown that Black, Asian and Minority Ethnic and Minority ethnic women are more likely to experience lower quality of care, poorer health outcomes and higher maternal and perinatal morbidity rates, when compared with white women. In addition to this, Public Health England reports indicate that mortality and serious complications from Covid-19 disproportionately affect those from a Black, Asian and Minority Ethnic background. Black women are eight times more likely and Asian women four times more likely than a white woman to be admitted to hospital with Covid-19.²

Following engagement and advocacy from Bristol Women's Commission, the CCG has now developed a maternity strategy for Black, Asian and Minority Ethnic women.

Bristol Women's Commission supports the 'Five Steps' campaign for health professionals (developed by Royal College of Obstetricians and Gynaecologists and Five X More³) to improve care for Black, Asian and Ethnic Minority women to change attitudes and eliminate inequalities:

1. Listen
2. Remove any barriers to communication
3. Check you are providing clear information
4. Provide access to detailed documentation
5. Be a champion

¹ Bristol Self-Harm Surveillance Register Annual Report 2018 - https://cpb-eu-w2.wpmucdn.com/blogs.bristol.ac.uk/dist/3/343/files/2019/09/BSHSR_AnnualReport-27062019-PRINT.pdf

² Perinatal support for Black, Asian and Minority Ethnic and Minority Ethnic women during Covid pandemic, joint guidance from North Bristol Trust and University Hospitals Bristol.

³ <https://www.rcog.org.uk/en/news/campaigns-and-opinions/race-equality-taskforce/five-steps-for-healthcare-professionals/>

1.3 Menopause

Menopause support

The Bristol City Listening Project research⁴ revealed that many women are concerned about the availability and quality of menopause support services. We heard negative experiences of healthcare professionals, especially GPs. Women told us how they had visited GPs seeking support for menopausal/peri-menopausal symptoms and had been prescribed hormone replacement therapy (HRT) without any accompanying advice on the impact of HRT or alternative treatment options.

There is patchy coverage of menopause specialist centres across England, e.g. 12 in London, less than 10 for the whole of North England. Only 10% women in menopause take HRT. This low take-up is influenced by anxieties around breast cancer, legacy of media shock stories, and misquoting scientific research in this area.

Intersection between menopause and women's mental health

40% women report not being prepared for mental health impact of menopause. Reports from a Bristol-based domestic/sexual abuse support organisation reveal that many of their clients accessing mental health support are either peri-menopausal or menopausal. During their admission, this topic often comes up and usually the women have spoken to their GPs etc but not been given any practical advice. The organisation now offers sessions on menopausal symptoms/depression etc as this seems to be an area that is often missed out on with GPs. One client in particular was given anti-depressants for depression even though she was fully aware that the menopause, not depression, was causing her symptoms.

Menopause and the workplace

Bristol Women's Commission has been working for several years to influence employment policy around the menopause in Bristol. We have been supported in this work by our sister organisation, Bristol Women's Voice, who have run menopause workshops and worked with communities to understand women's lived experiences of the menopause and the type of support they require at work.

Based on our research with working women experiencing the menopause, Bristol Women's Commission strongly argues for robust **menopause policies** to be developed and adopted by all employers. In combination with menopause policies,

⁴ Bristol City Listening Project – full report available here (*names have been changed for confidentiality): <https://www.bristolwomensvoice.org.uk/project/city-listening-project/#:~:text=In%20summer%202019%20Bristol%20Women's,contribute%20to%20better%20policy%2Dmaking>.

we advocate for **mandatory training for managers** and awareness raising sessions for all employees about menopause and the workplace.

2. Incontinence and Pelvic organ Prolapse

Pregnancy and childbirth can damage the pelvic floor leading to disturbances of the bladder, bowel, sexual function. From these, urinary and faecal incontinence and utero-vaginal prolapse may arise. Estimating the exact UK prevalence of incontinence is difficult as it is reliant on disclosure which is notoriously poor due to the embarrassing nature of symptoms. However, it is known that over 14 million adults experience urinary incontinence and 6.5 million experience bowel control difficulties in the UK.⁵

Earlier identification and management can save costly years with incontinence from a personal perspective: e.g. quality of life and cost of incontinence pads (£226 million per annum spent by individuals on continence products), and societal perspective. Indeed, there is increased cost to health and social care from falls, skin breakdown, infections, hospital admissions, delayed discharges, placement in nursing or residential care all associated with incontinence, aside from the £700 million annual NHS spend associated directly with incontinence. In women over the age of 80, many affected women are unable to look after themselves at home, particularly if cognition is affected, and are looked after in residential institutions.⁶

More recently the issue of **Pelvic Mesh Implants** used in the surgical repair of pelvic organ prolapse and management of incontinence has emerged. This procedure has been linked to a long list of life changing complications including chronic pain, reduced mobility, loss of sex life, recurrent urinary symptoms, and impact on mental health.⁷ A review launched in the House of Commons in 2018 to investigate this and two other medical treatments associated with women's health reported that long-term monitoring of outcomes was lacking, affected women had been dismissed and ignored, and the healthcare system is disjointed, siloed, unresponsive and defensive in its ability to identify when things are not going well. As summarised by a patient interviewed in the review process: "The person I once was, she has gone and no-one seems able to help me. No-one is listening."

⁵ NHS England, *Excellence in Continence Care: Practical guidance for commissioners, and leaders in health and social care* (2018)

⁶ Elneil in Davies (2015) p. 124

⁷ Cumberlege, J., *First do no harm: the report of the Independent Medicines and Medical Devices Safety Review* (2020)

3. Awareness and Understanding of Women's Health Issues

3.1. WOMEN

Not Feeling Listened to

Women report feeling unheard by medical professionals

We hear that many women feel they are not listened to because the health practitioner considers themselves better educated. These can be fears and perceptions of the individual or based on actual experiences. One woman stated that due to the medical professional coming from a good upbringing and being intelligent she felt unheard and not believed when discussing her mental health and traumatic experiences. It was to the extent that the individual used her own funds to seek professional medical support and assessment.

Medical experiences of women with less visible/hidden long-term illnesses

In the Bristol City Listening Project, most of the women with chronic illness spoke about a lack of support through their doctors and within NHS services more broadly. We heard how women were being sent away from their GP practices without any support or follow-up treatment. All but one woman who had a hidden/less visible illness had struggled to get their condition recognised and taken seriously through health services, resulting in a sense of systemic failure regarding healthcare. We heard from women with chronic health conditions who had found themselves being passed between services without receiving any treatment.

Diagnosis challenges

We know from both national reports and local research that women often endure lengthy and complicated processes before receiving a diagnosis; for example, women have to wait an average of eight years before being diagnosed with endometriosis. From listening to women in Bristol, we hear that many women don't feel listened to or believed by medical professionals and this often leads to them not receiving the diagnosis, care and treatment they require within suitable timeframes. Building on this qualitative research, it is important to consider quantitative data around primary and secondary care referral rates to understand how and where women are falling through gaps in the diagnosis pathway.

Negative stereotyping of women with mental health issues

We hear from women who say they feel their concerns have been dismissed or they have been judged because of their presentation around mental ill health. Myths around women being seen as 'attention seekers' or 'hysterical, over emotional' still persist from some health care providers and have a negative impact on the health of women we work with and these experiences can stop women from seeking help.

Differences in healthcare professionals' treatment of women vs support staff

A Bristol-based organisation supporting women experiencing domestic and/or sexual violence and abuse tell us that they frequently see their clients being treated

differently by healthcare professionals depending on whether or not a support worker is present in appointments. For example, a woman with substance misuse had an emergency script for methadone. When the pharmacist wasn't aware that the client was with a support worker, they used language that seemed to patronise and shame the woman who was seeking support causing distress. When the support worker stepped in and advocated for the young woman, their tone changed and the client was given the help she needed.

Women not being listened to re genital medical issues

We heard from a partner organisation about a woman with depression and anxiety who has been unwell with a cyst flare up, this cyst is on her genital area but not related to an STD or any other female-specific body parts. It's a regular cyst which could occur in any part, however she related that as soon as she told male doctors where the location of the cyst was they stopped listening and were not particularly helpful. When she called 111 the operator tried to refer her to a sexual health clinic despite her saying it wasn't related to sexual health as this had already been explored.

3.2 Training and Research about Women's Health

GP training on women's health

It is crucial that GPs receive ongoing, compulsory training around women's health and female health conditions. This will create an empathetic, supportive and informed environment in which women feel comfortable coming forward to discuss issues, focusing on prevention rather than being reactive. This will also help counter the criticism that many women feel that they are not fully listened to by GPs and primary healthcare staff.

Chronic health conditions which disproportionately affect women

It is reported that almost all autoimmune diseases affect women more than men, with lupus as a key example. Long-term health conditions characterised by persistent pain and chronic fatigue, for example fibromyalgia and M.E., also disproportionately affect women. Under-researched for many years, it is vital that attention and funding is directed towards better understanding these chronic health conditions in order to improve the long-term health and well-being of women in future. With chronic pain and fatigue appearing as significant symptoms in Long Covid (which itself is more commonly experienced by women), it is especially timely to research these aspects of health with a gendered view.

Rosie*, a woman who has been unwell with chronic fatigue, and related health issues, for many years talked about the lack of awareness around hidden and chronic illnesses: "No-one understands how systematic the illness is – it affects every bit of your being". Women reported that chronic illness has a negative effect on many aspects of their lives, including mental health, relationships, isolation, transport, work, and finances. They also shared that not many people understand

the fluctuating and unpredictable nature of chronic illness, which means that accessing employment (and/or financial support) is a particular challenge.

Autism in women

We understand that the usual diagnostic and assessment processes for autism are likely to have unconscious bias towards diagnosing boys and young men. Girls and young women are more likely to receive a diagnosis of social anxiety.⁸

We recently heard about a woman with PTSD who has been trying to get an assessment for autism. She feels that it is harder for women as the information, signs, and traits are based on men's experiences and presentation of autism. She recognises many of the symptoms from her own research but has been unable to be diagnosed and feels dismissed. She also feels that potentially having undiagnosed learning disability has made her more vulnerable to exploitation and abuse in the past.

Alzheimer's Disease/dementia is the biggest killer of women aged 70+. There is very little research into the effect of reduced oestrogen on brain health which could help towards prevention of, and/or better drug treatments for, dementia.

Black, Asian and Ethnic Minority women

Reports from partner organisations reveal that many Black, Asian and Ethnic Minority women don't access the health support they need due to language barriers, fear of accessing health care due to previous experiences of racism and a lack of trust in health care research and understanding of black and minority ethnic women. We hear women say they feel if they go to a health professional they could be labelled with a mental health diagnosis that would then be used against them, or that by seeking help with their mental health they risk being ostracized from their community.

Other women say that they could be given medication and treatment that will cause them further harm; some women feel strongly that it is designed to cause harm to black and minority ethnic women.

Advice around domestic violence and abuse (DVA)

We hear that some women who have sought support around domestic abuse from a health professional have felt unsupported and given the wrong advice. Reports include women being offered mediation as a path to resolution; men being advised to have anger management support. This has caused further distress for the women as they question whether they have indeed been a part of the problem. It is a misunderstanding of the causes of DVA and increases risk as well as the barriers to accessing support, as women are unsure whether their partner can help what they are doing due to anger, or whether it can be mutually resolved which can give more power to the perpetrator.

⁸ Professor Francesca Happé's research on girls and autism

An example of good practice in this area is the **IRIS programme** (<https://irisi.org/>)⁹ which delivers training to clinical and non-clinical staff on domestic violence and abuse where women and children are victims. When trauma-informed training is delivered, there are increased referrals and an increase in health professionals seeking advice for patients. Similar training is also delivered to A&E staff which has a similar impact. Involving women with lived experience in training and co-production of the services results in greater impact and should be central to any service development.

However not all practices are signed up to IRIS training and not all health professionals attend. There is a further need for this training in other hospital departments and sexual health clinics. Attention must also be paid to which groups are able to access DVA support and how. For example, a Bristol-based domestic/sexual abuse support organisation reports a very high level of women from under-represented groups seeking support, apart from through the IRIS programme which relies on staff at GP practices making referrals. This highlights that women from these groups seem less likely to go to a GP.

Additional Issues

3. Mental Health

Mental health services

The Bristol City Listening Project research showed that many women experienced long waiting lists for free or reduced rate counselling. We heard how women had waited up to 12 months to access counselling through the NHS. Women reflected that NHS mental health services are reactive, rather than proactive in supporting people before they reach crisis point. This feeling was especially prevalent in areas with higher levels of deprivation. A number of women told us that they had been unable to access services when they became aware that they needed support; for some of these women the impact of this has been devastating, resulting in suicide attempts. This feeling of inadequate support was echoed in women's experiences of receiving counselling and mental health support through the NHS, with many highlighting the problems produced by the cap on available sessions. Nikki* spoke about her experience of being restricted to six counselling sessions before she had to go back on the waiting list: "Services are not there to support you to make long-term change which takes account of people's histories in order to bring about long-term change".

Black, Asian and Ethnic minority communities and mental health

Evidence shows that more Black women report low mental health than white women, but less frequently seek help/support/advice (cited in Bristol, North Somerset and South Glos CCG Mental health framework spec).

⁹ Developed at University of Bristol - <http://www.bristol.ac.uk/research/impact/iris-training-helps-victims-of-domestic-abuse/>

The Bristol City Listening Project supports this finding, and recommends a focus on:

- Ensuring that mental health services are adequately reaching Black, Asian and Minority Ethnic communities in Bristol and looking to create funding specifically for Black, Asian and Minority Ethnic mental health service providers;
- Using established community representatives to reach out to Black, Asian and Minority Ethnic communities in order to better understand the most helpful format for any future mental health support programmes.

Young women and mental health issues

It is increasingly evident that more young women are experiencing mental health and anxiety, especially since lockdown, and there isn't enough funding or resources to ensure these individuals are assessed and treated in a good time frame. Waiting lists are too long and there seems to be less priority, which in turn affects these young individuals long-term. There are exceptionally long waiting lists for specialist sexual violence counselling. Thresholds for support around mental health within statutory services seem higher.

Trauma-based counselling

In the Bristol City Listening Project, we heard many stories about the need for longer-term approaches to mental health support. For example, Asya* told us how she had received NHS trauma-based counselling after she was treated for a suicide attempt. Key to the success of this treatment in Asya's eyes was the long-term nature of the support, which enabled her to address deep-rooted childhood trauma.

Challenging stigma

Bristol Women's Voice have been proactively breaking down the barriers around talking about mental health by running workshops on 'Recognising the Signs and Busting the Stigma Around Women's Mental Health'.¹⁰

Intersection between domestic/sexual violence and women's mental health

We hear that many women accessing domestic support services also receive treatment and support with mental ill health, including being in and out of hospital, and they have often never been asked about experiences of domestic or sexual abuse. We have had some examples of women who have disclosed they are in an abusive relationship and yet no further questions were asked about how to support them with their safety, get them help, or the link between being abused and presenting with mental ill health.

We also find that some perpetrators are also carers for women with mental ill health, and use this as another tool to control and isolate her. They will attend all health appointments and speak on behalf of the victim.

A Bristol-based domestic/sexual abuse organisation reports that many clients who access support for mental ill health have a diagnosis of EUPD [emotionally unstable

¹⁰ <https://www.bristolwomensvoice.org.uk/project/womens-health/>

personality disorder] on their referral form, although on further investigation they often do not have this as a formal diagnosis and it appears to be a diagnosis that is given to women informally. Some of the women we support don't seem to fully understand what this informal diagnosis means, and how to navigate and get support with it. Most of the women who have this written on their referral have also experienced significant trauma and have complex PTSD.

5. Domestic Violence and abuse

It is proven that domestic violence and abuse (DVA) has a significant impact on women's health; if correctly and quickly recognised, this can help with early intervention for women experiencing DVA and also prevent further health issues.

Older women and DVA

Recognising that elderly women are just as likely to be experiencing DVA and rape and sexual assault, as well as the mental ill health caused by this, or care and support needs that make them more vulnerable to being abused, needs to be a priority group as much as any other age group.

A Bristol-based domestic/sexual abuse support organisation reports increasing numbers of older women accessing domestic abuse services through a GP practice, compared to very few over 3 years ago. However, many of these women describe missed opportunities for disclosure in the past, due to feeling like they were seen as an older woman and dismissed by professionals as being 'difficult, frail, overly anxious or overly demanding of their family/partner'. Some women said that, despite disclosing extreme control – such as not having access to their finances or not being allowed out at certain times – this has been viewed as a cultural and traditional family life rather than domestic abuse.

Domestic/sexual violence policy in the workplace

Many workplaces don't have a domestic or sexual violence policy. A local domestic/sexual abuse support organisation reports that many women they support have had significant time off work due to either made-up health care issues because the perpetrator isn't allowing them to go to work, or multiple health issues caused by DVA. Many of these women struggle with depression and PTSD and aren't given the support they needed, meaning they have had to leave employment by the time they access DVA services. If they are still in employment when being supported, professional advocacy highlighting their mental ill health and experiences of trauma is often very successful in them adjusting their employment so they can continue to work.

Flexible working arrangements, wellbeing action plans and safety plans around domestic abuse risks all help women experiencing DVA to stay in their employment.

When employers receive training around trauma-informed management, this is beneficial to all staff; specific needs of women should be central to this.

Impact of DVA on female carers' employment

We hear that many women accessing DVA support don't feel they can work due to being the sole carer. Those that do often have to have time off work due to their children's needs, being sick and off school, and having no family to rely on. Many women describe exhaustion at being sole parents, often for children who have additional needs due to experiencing trauma and/or SEND, and they don't have the physical or mental capacity to focus on their work or career. This 'carers' burnout' affects women's health and work.

6. Impacts of COVID-19 on Women's Health

Domestic abuse increase during lockdown

The increase in Domestic Abuse during lockdown by over 35% has had a big impact on women's health alongside increased isolation, fewer resources available to help support women at risk and women who are sole carers, and more women presenting with mental ill health.

Research by Counting Dead Women calculated at least 16 domestic abuse killings of women and children had taken place in the first three weeks of lockdown. This is double the average rate and the largest number of killings in a three-week period for a decade.

Certain legal duties were removed under temporary changes to the Care Act (2014) resulting in less access to care provision due to prioritisation of people with greatest care needs. This may impact people with caring responsibilities, e.g., survivors who are caring for perpetrators or perpetrators who are caring for survivors.

Self-harm during pandemic

Research has shown that young women have experienced the highest levels of distress during the coronavirus crisis, with specialist services raising particular concerns about the impact of the pandemic on Black and ethnic minority young women. Rates of self-harm are highest amongst young Black women (16-34) but they are less likely to receive support for this. Studies suggest South Asian young women (16-24) are significantly more likely to self-harm than white young women.¹¹

Black, Asian and Minority Ethnic communities and Long Covid

There is recent evidence showing that women who have had Covid-19 are more at risk of developing Long Covid. In Bristol, there are reports of low numbers of Black, Asian and Ethnic Minority people attending the new Long Covid Clinic. Therefore,

¹¹ See <https://weareagenda.org/wp-content/uploads/2020/11/Struggling-Alone-3.pdf>

women of Black, Asian and Ethnic Minority origins with Long Covid are likely to not be proportionally represented in patient numbers here.

Black Asian, and Minority Ethnic communities and bereavement

There is likely to be more experience of bereavement among many Black, Asian and Ethnic Minority communities due to Covid-19. There is a low take-up of grief-specific counselling support by people of Black, Asian and Ethnic Minority origins (cf: Cruse Bereavement reporting). Attending funeral services has not been possible due to lockdowns. Thus, there is the possibility of unresolved grief leading to ongoing trauma, anxiety, depression. There is also evidence of low take-up of counselling/therapeutic support by women of many Black, Asian and Ethnic Minority communities, e.g. due to lack of cultural sensitivity, languages other than English, flexible times of appointments.

Contact Details

For further information or any questions, please contact **Penny Gane**, Chair of Bristol Women's Commission on pennygane.bwc@gmail.com.

Information collated and edited by Alice Clermont from BWC Health Task Group