CROHN'S & COLITIS UK

Women's Health Strategy: Call for Evidence

Submission from Crohn's & Colitis UK, June 2021

About Inflammatory Bowel Disease

Ongoing research is revealing that over 500,000 adults and children in the UK have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis. IBD is a painful, debilitating and lifelong condition. Symptoms include urgent and frequent diarrhoea (often with blood and mucus), abdominal pain, fatigue and weight loss, with associated anxiety and depression.

They lead to time of school and work, withdrawal from social relationships and inability to carry out everyday activities, such as shopping and exercise. IBD doesn't just affect the gut, it can affect almost every part of the body and every aspect of life: from digestion, eyes and joints to energy levels and mental health. Lack of public understanding of Crohn's and Colitis can lead to stigma and discrimination.

While the numbers of males and females with IBD are broadly similar, there are a range of important differences that need to be taken into consideration in the healthcare of females with IBD.

Crohn's & Colitis UK

As the leading charity for Crohn's and Colitis in the UK, we work to improve diagnosis, treatment and care, to fund research into a cure, to raise awareness and to provide information and support.

We welcome the opportunity to respond to this consultation. Our key recommendations are set out below. While these relate to females with IBD, many of the themes will be relevant to other long-term condition areas. We would like to see targets for improvement in some of the key areas of women's health identified, which are measured on an ongoing basis, including through Patient Reported Outcome Measures.

- To avoid unacceptable **delays in diagnosis** for females presenting to GPs with gastrointestinal symptoms, IBD should be considered and investigated in line with the IBD Standards and local referral pathways and protocols.
- The **wider symptoms of IBD**, including fatigue, extraintestinal manifestations and depression, which affect females disproportionately, need to be discussed as part of developing a personalised care and support plan, with specialist care and support provided as needed.
- The **potential impact of IBD on puberty, menstruation, sexual health, fertility, family planning, the menopause and cervical screening** need to be discussed, supported by patient education, as part of self-management, which meets national standards for every woman with IBD. We would like to see a national review of family planning and reproductive services for people with long-term conditions as part of the Women's Health Strategy and clearly defined referral pathways from all specialist services.
- **Shared decision making about treatment options** should take into account gender-specific treatment considerations, for example, in relation to drug side effects, adherence and surgical outcomes and potential impact on fertility.

- **More research is needed to improve our understanding of gender differences in IBD** to support effective treatment and high-quality personalised care, for example developing our understanding of vulvar Crohn's. We would like to see a defined commitment to a specific target for increased investment in research.
- **Healthcare provision needs to support the specific needs of females with IBD,** who may have increased childcare responsibilities and be managing work and have little or no support from a partner. More flexible and responsive approaches are needed, with proactive education and support for self-management.

1. Diagnosis

Recent results from a UK-wide assessment of the quality care from both people with IBD and specialist IBD services found significant delays to diagnosis with 41% of patients reporting visits to Accident and Emergency Departments prior to diagnosis.[1] Most people are diagnosed with IBD between the ages of 15 and 40, although IBD can develop at any age. One of the challenges of recognising possible IBD for general practitioners is the fact that symptoms can be associated with a range of other conditions. These include irritable bowel syndrome, bowel cancer, coeliac disease, eating disorders, endometriosis and ovarian cancer. Given some of these conditions are specific to females, this could lead to greater potential for misdiagnosis in girls and women. Free text responses to the IBD Patient Survey revealed that some females with IBD did not feel that they were taken seriously. Below is an example of one woman's experience of diagnosis.

> *"I am a 37-year-old British-Asian woman who has lived with ulcerative colitis for over 13 years. My first symptoms occurred aged 24. I noticed blood in my poo and knew something wasn't right so I went to the GP. Over two years, I had many appointments and saw different consultants at different hospitals, with varying degrees of quality of care. Over two years I lost a lot of weight, struggled to eat, I was often in the toilet up to 20 times a day and doubled over in pain, I was bleeding from my bowels, my sleep was affected, and I constantly felt exhausted. All areas of my life were impacted, including my work, hobbies and social life. My mental health was also affected, and I was given little support for this. I felt like I'd been pushed from pillar to post over two years with a variety of prognoses and no clear information, support or plan for how to manage my health. It was not only a difficult time for me but also my family, who could see the devastating impact this condition was having on me.*
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> *I was finally given an official diagnosis of ulcerative colitis. I remember being told that there was no cure and that I would have to live with the condition for the rest of my life. I cried. I cried with despair at the thought of having to live the rest of my life as I had been for the past two years, but I also cried with relief at finally being given a diagnosis and feeling like I'd been listened to and believed. The gastroenterologist and I discussed a plan aimed at bringing my symptoms under control, which gave me hope. I believe two years was too long to receive a diagnosis. In that time, the impact on my daily life was immense."*
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> Anisha, diagnosed with Ulcerative Colitis in 2008

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[1] IBD UK, *Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change*, April 2021. Crohn's and Colitis Care in the UK: The Hidden Cost and a… | IBD UK

Delayed diagnosis leads to reduced response to medical treatments and higher incidence of urgent and emergency surgical intervention.[2] More education is needed to upskill community healthcare professionals about IBD and referral pathways need to be in place between primary, secondary and emergency care to support timely, appropriate detection, diagnosis and treatment.

2. IBD-related complications and conditions outside the gut, fatigue and mental health

Up to 50% of people with IBD will experience extraintestinal manifestations, involving different parts of the body, commonly joints, skin, bones, eyes, kidneys and liver.[3] Females with IBD are more likely than males with IBD to experience extraintestinal manifestations.[4] Prevalence of depression in IBD is also higher in women than in men, and considerably higher than in the general population.[5] Additionally, self-reported quality of life is lower in females with IBD than in males with IBD.[6]

Females with IBD are also more likely to experience fatigue than males, with both frequency and intensity of fatigue more prominent in the females.[7,8] IBD has a negative impact on body image, which is greater in females than males. However, despite the significant impact of these issues, results from the UK-wide IBD patient survey found that 60% were not asked about mental health during medical appointments and 48% were not asked about fatigue. 47% were not asked about IBD-related complications or conditions outside the gut.

The IBD Standards set out that, after diagnosis, everyone with IBD should have a full assessment of disease, nutritional status, bone health and mental health, to develop a personalised care plan. However, only 10% reported that how well they were coping emotionally had been assessed following diagnosis. 89% reported having felt unable to cope with having Crohn's or Colitis over the previous year. Those who said they were asked about complications outside the gut, pain, fatigue and mental health were more likely to rate the quality of their care highly and report feeling more able to cope indicating the importance of this to people. Females were less likely than males to rate their care highly overall.

There is a clear need for greater focus on these issues as part of healthcare to enable females with IBD and other long-term conditions who experience similar concerns, to manage and live well with their condition.

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[2] Lee DW, Koo JS, Choe JW, et al. *Diagnostic delay in inflammatory bowel disease increases the risk of intestinal surgery.* World Journal of Gastroenterology. 2017. 23: 6474-81. https://doi.org/10.3748/wjg.v23.i35.6474.

[3] Harbod M, Annese V, Vavricka SR. *The first European evidence-based consensus on extra-intestinal manifestations in inflammatory bowel disease.* 2015. Journal of Crohn's and Colitis. 10(3):239-254. https://doi.org/10.1093/ecc-jcc/jjv213.

[4] Severs M, Spekhorst LM, Mangen MJ, Dijkstra G, Löwenberg M, Hoentjen F, et al. *Sex-Related Differences in Patients With Inflammatory Bowel Disease: Results of 2 Prospective Cohort Studies*. Inflammatory Bowel Diseases. 2018 May;24(6):1298–306.

[5] Häuser W, Janke KH, Klump B, Hinz A. *Anxiety and depression in patients with inflammatory bowel disease: comparisons with chronic liver disease patients and the general population*. Inflammatory Bowel Disorders. 2011 Feb;17(2):621–32.

[6] Hauser G, Tkalcić M, Stimac D, Milić S, Sincić BM. *Gender related differences in quality of life and affective status in patients with inflammatory bowel disease*. Collegium Antropologicum. 2011 Sep;35(Suppl 2):203–7.

[7] Saraiva S, Cortez-Pinto J, Barosa R, Castela J, Moleiro J et al. *Evaluation of fatigue in inflammatory bowel disease - a useful tool in daily practice*. Scandinavian Journal of Gastroenterology. 2019 Apr;54(4):465–70.

[8] Bager P, Befrits R, Wikman O, Lindgren S, Moum B, Hjortswang H, et al. *Fatigue in out-patients with inflammatory bowel disease is common and multifactorial*. Alimentary Pharmacology and Therapeutics. 2012 Jan;35(1):133–41.

3. Menstruation and menopause

The hormonal changes during the menstrual cycle may affect disease symptoms for those living with IBD.[9] In girls, puberty may be delayed, particularly if they are malnourished.[10] For those menstruating, an increase in diarrhoea during periods has been reported.[11] Painful periods can be exacerbated by IBD and there is potential for these to be mistaken for flare-ups of the underlying IBD if people are not made aware of this. Discussing these also enables females to prepare for and manage these fluctuations more positively. However, currently, this is often not addressed as part of treatment and care for IBD, with the provision of information highly variable. Standardised education in this area is needed. There is little research available on menopause and IBD, but similar issues may occur with understanding whether fatigue and other symptoms experienced relate to the menopause, to the IBD, or to both at the same time. More research is needed in this area.

4. Sexual health

Living with Crohn's or Colitis can have an impact on your relationships and sexual activity. Some of the symptoms of Crohn's or Colitis may make sex more difficult emotionally, physically or both. For example, fatigue or extreme tiredness, abdominal pain, abscesses, fistulas or scarring of the skin around the anus or vagina, may lead to reduced interest in sex or cause this to be more uncomfortable. Fears around having accidents, such as a bout of diarrhoea during sex, changes in how people feel about their body after surgery, side effects from steroid medication and depression related to Crohn's or Colitis can cause sexual difficulties, such as changes in sexual satisfaction.

In one study, 50% of women reported worsening sexual function after diagnosis of IBD, compared with 33% of men and depression was cited as the major factor.[12] Information and discussion about sexual wellbeing, as well as screening for depression are therefore an important aspect of care and support for women with IBD, which are often overlooked and seen as taboo in IBD management, with a lack of pathways and referrals to appropriate specialists.

5. Family planning

The combined oral contraceptive pill and the progestogen-only contraceptive pill may be less reliable if you have Crohn's or Colitis and malabsorption, which is impaired absorption of nutrients and drugs from the gut into your body. Women with IBD taking oral contraceptives can also be at increased risk of developing blood clots.

Having surgery, staying in hospital and not moving much are risk factors for blood clots. Women with IBD should therefore be advised to stop taking combined oral contraceptives at least four weeks before and use other methods of contraception. Additionally, surgery for Crohn's or Colitis could have an impact on the safety and success of laparoscopic sterilisation surgery.
Information about these important considerations is often not proactively provided – this needs to be improved, with consultations focused more on the broader issues of concern to women with IBD than purely medication and bowel symptoms.

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[9] J. Moore, D. Barlow, D. Jewell, and S. Kennedy, *Do gastrointestinal symptoms vary with the menstrual cycle*? British Journal of Obstetrics and Gynaecology, vol. 105, no. 12, pp. 1322–1325, 1998.

[10] A. B. Ballinger, M. O. Savage, and I. R. Sanderson, *Delayed puberty associated with inflammatory bowel disease*. Pediatric Research, vol. 53, no. 2, pp. 205–210, 2003.

[11] M. T. Bernstein, L. A. Graff, L. E. Targownik et al., *Gastrointestinal symptoms before and during menses in women with IBD*. Alimentary Pharmacology and Therapeutics, vol. 36, no. 2, pp. 135–144, 2012.

[12] L. Marín, M. Mañosa, E. Garcia-Planella et al., *Sexual function and patients' perceptions in inflammatory bowel disease: a case-control survey*. Journal of Gastroenterology, vol. 48, no. 6, pp. 713–720, 2013.

Women with IBD may be concerned about the impact of IBD on fertility, pregnancy and birth. Ideally, disease should be in remission when conception occurs and during pregnancy for the best prognosis for both mother and baby and most medications can be continued to support this. Active disease may cause lower rates of fertility as can surgery, although fertility should otherwise be the same as for the general population.

Despite this, studies have shown that women with Crohn's or Colitis are more likely to decide not to have children, perhaps because of worries about the impact of Crohn's or Colitis on pregnancy, as well as concerns about passing on Crohn's or Colitis to children.

> *"At one point, I considered not having any children as I was worried that having Crohn's would affect my baby. I am so pleased we decided to though, as we are now parents to two healthy children."*
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> Debbie, age 31, mother to two children, diagnosed with Crohn's in 2002

Full information and support should be provided to females with IBD to support shared decision making prior to surgery, as set out in the IBD Standards. As some studies have found that the risk of infertility is lower in people who have had laparoscopic surgery, this should be offered as an option. However, there is currently variable access to laparoscopic surgery for IBD. An opportunity to discuss implications with a fertility specialist should be offered.

Given potential complications associated with pregnancy, it is vital that effective joint management takes place between the specialist gastroenterology team and high-risk obstetricians. However, this is often not available to women with IBD.

6. Cervical cancer

Women taking immunosuppressive drugs for their IBD have an increased risk of contracting the human papilloma virus (HPV) - the virus that causes cervical cancer.[13] They should therefore be strongly advised by their specialist team to ensure they have cervical screening when invited. This is another aspect which is often not addressed.

7. Gender-specific treatment considerations

Some gender differences have been reported in relation to different treatments.[14] Adherence to treatment is reported to be lower in females, who also are more likely to experience side effects of biologic drugs. Regarding surgery, higher rates of postoperative recurrence have been documented. This demonstrates the need for consideration of these differences as part of shared decision making about treatment options and for research and clinical trials to ensure that data is collected which improves our understanding of these differences to support effective treatment and high-quality personalised care. We also want to see investment into treatments for women with specific conditions such as Crohn's of the vulvar.

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[13] S. Kane, B. Khatibi, and D. Reddy, *Higher incidence of abnormal Pap smears in women with inflammatory bowel disease*, The American Journal of Gastroenterology, vol. 103, no. 3, pp. 631–636, 2008.

[14] Greuter T, Manser C, Pittet V, Vavricka SR, Biedermann L, on behalf of Swiss IBDnet, an official working group of the Swiss Society of Gastroenterology. *Gender Differences in Inflammatory Bowel Disease*. Digestion 2020:101(suppl 1):98-104. https://doi.org/10.1159/000504701.

8. Healthcare provision to meet the needs of women with IBD

It can be difficult for women with IBD to attend outpatient clinic appointments and receive drug infusions which take place at set times, given childcare responsibilities, especially if these fall during work hours. There are considerable opportunities to offer more flexible and responsive services which better meet the needs of women with IBD.

- Proactive provision of patient education to support self-management – e.g. through an online programme and/or education sessions at weekends and/or evenings.
- Use of technology to enable effective remote monitoring from home or close to home at times which are convenient to the woman with IBD (for example, regular faecal calprotectin and symptom monitoring from home, blood test access during non-working hours).
- Potential for subcutaneous treatment, at home, where appropriate.

9. Access to health services during the coronavirus pandemic

Crohn's & Colitis UK conducted a survey of the experiences of people with IBD during the pandemic between June and July 2020.[15] This found people with IBD were experiencing difficulties in accessing IBD teams, delays to investigations such as endoscopy, and were largely unable to have planned surgery for IBD.

Now, as the NHS attempts to clear the backlog created, we are receiving regular calls from people who are unable to get hold of their IBD team and receive the care they need. This is causing considerable anxiety and is likely to have significant long-term consequences for the mental and physical health of those affected. As women with IBD are more likely to suffer from depression, this could be expected to have a greater negative impact on their wellbeing. Clear communication and the adoption of new approaches to support self-management and remote monitoring are vital, as well as mental health support.

10. Conclusion

The issues ranged in this submission highlight a pressing need for proactive information provision and guidance for women with IBD about potential changes in puberty, menstruation, fertility, pregnancy, sexual health and the menopause, as a fundamental part of their care. Mental health, fatigue and IBD-related complications and conditions outside the gut need to be assessed and treated in addition to bowel symptoms and diagnosis needs to be improved.

We would like to see:

- A national review of family planning provision for women with IBD and other long-term conditions
- A commitment to measurable targets for improvement in information and support for these "women's issues" in the context of long-term condition management, with regular assessment, including patient-reported outcome measures.
- Increased research into gender-specific treatment considerations

For further information, please contact policy@crohnsandcolitis.org.uk.

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[15] Crohn's & Colitis UK. *Life in Lockdown Survey: What patients told us about their healthcare*. Life in Lockdown: What patients told us about their healthcare | Crohn's & Colitis UK (crohnsandcolitis.org.uk)