

Health, Social Care and Sport Committee inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales

Response from Crohn's & Colitis UK

Summary of key points and recommendations

- During the coronavirus pandemic, people with Crohn's and Colitis have experienced delays in diagnosis, access to specialist advice and medicines, drug monitoring and surgery - plans need to be put into place to ensure that services run continuously in the future.
- Information and advice from government to individuals about shielding needs to be more effectively targeted and coordinated with messages from patient organisations and specialist healthcare professionals - support is necessary for the vital role of patient organisations given the significant increase in calls to helplines.
- In resuming services, it will be important to ensure that people with Crohn's or Colitis are appropriately prioritised for tests and treatments, including surgery, and mental health support, and that these are undertaken in safe Covid-free environments. Delays can have serious and lifelong detrimental impact and may even prove fatal, for example, through acute severe colitis, undetected bowel cancer or more complicated emergency surgery.
- Reshaping and refocusing services, including the use of virtual consultations and home or point-of-care testing, should be undertaken with patient involvement and in the context of a personalised care planning approach - consideration should be given to the potential barriers and enablers for these to be effective for all, including black, Asian and minority ethnic (BAME) communities.
- Public and other toilets need to be reopened to enable people with Crohn's and Colitis to be able to stay connected and healthy - in accordance with the principles and duties set out in the Public Health (Wales) Act 2017.

1. Introduction

About Crohn's Disease and Ulcerative Colitis

- 1.1 Recent research into GP records in Wales by the SAIL databank at Swansea University, completed just prior to the Covid-19 pandemic, revealed there to be at least 24,000 people¹ living with Crohn's Disease or Ulcerative Colitis in Wales. This

¹ Inflammatory Bowel Disease in Numbers: Understanding the Scale of Crohn's and Colitis in Wales, 2020, SAIL Databank and Crohn's & Colitis UK

is significantly higher than previous estimates of 15,000 and reflects the results of similar research conducted in Lothian² and Devon³.

- 1.2 The two main forms of Inflammatory Bowel Disease (IBD), Crohn's and Colitis are lifelong conditions affecting people of all ages which are most often diagnosed when people are in their teens or twenties. In Crohn's and Colitis, the gut becomes swollen, ulcerated and inflamed, causing debilitating symptoms including acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus) and severe fatigue.
- 1.3 There are also a wide range of extraintestinal manifestations, which can affect the joints, skin, bones, eyes, kidneys and liver and a significant psychological impact. People living with the conditions often face a lifetime of medication and, in many cases, major surgery. If poorly controlled, complications from Crohn's and Colitis can be fatal.
- 1.4 Around one in four people with Crohn's or Colitis are at increased risk of severe illness from Covid-19⁴. Additionally, due to the fluctuating nature of the conditions, and the numbers affected, many more will have needed treatment and care during the coronavirus pandemic, ranging from diagnostic tests to infusions, drug monitoring and surgery. Lifetime costs for Crohn's and Colitis are comparable to other major diseases, including heart disease and cancer⁵.

About Crohn's & Colitis UK

- 1.5 As the leading charity for Crohn's and Colitis, we work to improve diagnosis and treatment, to fund research into a cure, to raise awareness and to provide information and support.
- 1.6 We provide support through a range of activities and events, including helplines (phone, email, LiveChat and web), local networks, award-winning *Connect* magazine, information resources and education programme events. We have experienced an unprecedented increase in enquiries to our helplines during the pandemic - at the peak we experienced a four-fold increase in enquiries - and we have answered over 9,000 enquiries from across the UK since the pandemic began. With the NHS sending patients from all over the UK to us for information, including Public Health Wales, 1.4 million people have got the answers they needed from our online information pages so far this year. This is an increase of 60% over the same period last year and includes a 600% surge in visits to our website between 22nd-28th March. In many settings, hospital advice lines have not been operational and IBD nurses have been drafted to the frontline of critical care, so more people have depended on Crohn's & Colitis UK for advice on managing their conditions. At the same time, we have experienced a significant drop in income as a result of the impact of the pandemic on our fundraising activities.
- 1.7 Our evidence to this inquiry is based on an analysis of calls and emails to our helplines during the pandemic and the responses from 355 people living in Wales who completed our "Life in Lockdown" survey. It also draws on the results of a

² <https://gut.bmj.com/content/68/11/1953>

³ <https://fg.bmj.com/content/early/2020/07/08/flgastro-2019-101369>

⁴ <https://ibdregistry.org.uk/covid-19/>

⁵ Luces, C Economic Burden of Inflammatory Bowel Disease: A UK Perspective, Expert Rev Pharmacoecon Outcomes Res 2006 Aug;6(4):471-82. doi: 10.1586/14737167.6.4.471.

survey of IBD services, including eight services in Wales, which was conducted between 8th-14th April⁶, enabling us to compare the patient and service experience. We have also spoken to and included quotes from people with Crohn's or Colitis and healthcare professionals across Wales about their experiences - we are very grateful to all those involved.

2. Delayed diagnosis, access to specialist advice and medicines, drug monitoring and surgery

Delayed diagnosis and access to investigations

- 2.1 As a result of lack of awareness and understanding, stigma and waits for endoscopy, delays in diagnosis were already experienced before Covid-19 for many people with Crohn's or Colitis. One in three people said it took over two years to get their diagnosis, with this extending to five years for nearly one in five respondents to a survey by Crohn's & Colitis UK⁷. During the Covid-19 outbreak, many will not have been able to take the first step in visiting their GP. For those who were on the journey to diagnosis, we are aware of cancellations of referrals to specialists, lack of access to investigations, including endoscopy (in accordance with guidelines), and follow-up appointments being cancelled for those part way through investigations. With more than 18,000 diagnoses of Crohn's and Colitis made in the UK each year⁸, around 4,500 would normally have been made between April and June this year.
- 2.2 Delayed diagnosis increases the likelihood of surgery or more expensive and aggressive treatments and if left untreated can cause more serious complications, which might require emergency surgery, or can be fatal⁹. Uncontrolled disease activity also increases the risk of people with Crohn's or Colitis developing bowel cancer.
- 2.3 People awaiting confirmation of their diagnosis will be left without an understanding of their condition, or access to appropriate treatment or support. Some have described this to us as a feeling of being "abandoned" by the NHS and medical teams. A respondent to our "Life in Lockdown" survey from Wales, who has now been able to get a diagnosis, said

"I thought I had cancer and was very unhappy and helpless."

Patient with Ulcerative Colitis, Wales

"We cannot access colonoscopy/flexible sigmoidoscopy investigations locally. This has certainly meant a delay in diagnosis and escalation of treatment."

IBD nurse specialist, Wales

⁶ Kennedy NA, et al. Frontline Gastroenterology 2020;0:1–8. doi:10.1136/flgastro-2020-101520
<https://fg.bmj.com/content/flgastro/early/2020/06/15/flgastro-2020-101520.full.pdf>

⁷ Crohn's & Colitis UK's 2016 Charity Survey of UK members (Q.2)

⁸ CNg, S et al (2017) Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. The Lancet - <http://dx.doi.org/10.1016/>

⁹ Lee D- W, Koo JS, Choe JW, et al. Diagnostic delay in inflammatory bowel disease increases the risk of intestinal surgery. World J Gastroenterol 2017;23:6474–81.

Access to specialist advice

- 2.4 While patients have reported positive support from clinical teams, including individual calls in the early stages of lockdown, the redeployment of specialist teams, impact of self-isolation by healthcare professionals and increase in advice line activity has resulted in patients reporting difficulties in accessing care and advice and a lack of coordination of care. One of the eight services in Wales reported no IBD nurse provision following the onset of Covid-19¹⁰. The number of IBD specialist nurses required to support a good quality service is 2.5 WTE¹¹. At the same time, 50% of services surveyed (4/8) reported a greater than 50% increase in advice line activity¹².
- 2.5 Consequently, some people have reported being unable to contact their IBD team and did not have the information around the increased risks for them with the coronavirus and the action they needed to take. Nineteen percent (66/355) of respondents to our “Life in Lockdown” survey living in Wales reported that they had either had to wait longer than usual to speak to an IBD specialist or had not been able to speak to one at all. Twenty-five percent (87/355) had had appointments delayed or cancelled.
- 2.6 This has also been an issue for some people experiencing a “flare”, an exacerbation of symptoms, where they have been left without clear information on the action to take to manage the flare, including adjusting medication doses. Twenty six percent (91/355) of respondents to our “Life in Lockdown” survey living in Wales reported that changes to the healthcare system during the coronavirus pandemic have affected their ability to stay well with their Crohn’s or Colitis. This includes 16% (58/355) who reported having had a flare as a result. If untreated, this can lead to serious complications and worse long-term health outcomes. The cost of treating an outpatient in a flare is two to three times higher than treating a stable patient¹³.

Each year, Ulcerative Colitis care costs¹⁴:

- £1693 per patient in remission
- £2,903 per patient in relapse with mild-to-moderate Ulcerative Colitis
- £10,760 per patient in relapse with severe Ulcerative Colitis

Each year, Crohn’s Disease care costs:

- £1,800 for patients in remission
- £10,513 for patients in relapse

¹⁰ Ibid, page 3

¹¹ Modelling Caseload Standards for IBD Specialist Nurses in the UK, April 2017 http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Modelling_Caseload_for_IBD_CNS_CCUK_report.pdf

¹² Kennedy NA, et al. Frontline Gastroenterology 2020;0:1–8. doi:10.1136/flgastro-2020-101520 <https://fg.bmj.com/content/flgastro/early/2020/06/15/flgastro-2020-101520.full.pdf>

¹³ Bassi A, Dodd S, Williamson P Cost of illness of inflammatory bowel disease in the UK: a single centre retrospective study. <https://www.ncbi.nlm.nih.gov/pubmed/15361497>

¹⁴ Ghosh N, Premchand P. UK cost of care model for inflammatory bowel disease <https://www.ncbi.nlm.nih.gov/pubmed/28839807>

“I feel like I’ve been forgotten. I was due a clinic appointment, a 24 hrs fasting test in hospital and a scope in the stoma, but no appointments booked or any contact from the hospital. Basically, no communication from anyone, my GP included! I feel completely ignored like I don’t matter.”

Patient with Crohn’s Disease, Wales

Access to medicines and drug monitoring

- 2.7 During the Covid-19 outbreak, some patients have experienced issues with access to essential medicines, which can lead to a flare and further complications. In some areas, homecare medicines services, used to provide subcutaneous medicines direct to patients in their own homes, have not been available to new patients. There have also been issues with communication between homecare medicines services and hospitals. This has resulted in some patients with Crohn’s or Colitis being unable to access required medication when they needed it. Three out of the eight IBD services surveyed in Wales reported an inability to set up new homecare services for subcutaneous biologics and immune-modulatory therapy, while one also experienced disruption to the homecare delivery provision of therapies due to provider issues¹⁵.
- 2.8 While steps have been taken to ensure that infusions can be given as safely as possible in hospital, we are aware of some issues affecting both access and safety. One quarter of the IBD services surveyed in Wales (2/8) relocated drug infusion services to a ‘safer area’ away from acute services. Three of the eight services reported that patients had cancelled at least some of their scheduled infusions, either due to self-isolation or fears and concerns about the treatment.

“Unfortunately, there have been some delays for new patients starting on treatment either because of their own anxiety around doing so at such a time or because there has been reduced capacity in the Medical Day Unit.”

IBD nurse specialist, Wales

“I am fortunate that I have still had my infliximab infusions at hospital. I attend a different hospital for treatment than where my gastro team are based. However, in March, despite being in the high-risk group and told to shield, the nursing staff doing the infusions had no PPE whatsoever, despite having to get very close to you. I was anxious about going during this time anyway and had a terrible fortnight afterwards wondering if I had caught Covid-19. I was incredibly anxious about going for my next Infusion because of this experience. This time staff had PPE and were giving patients a mask.”

Patient with Ulcerative Colitis, Wales

- 2.9 We are also aware of delayed or cancelled vitamin B12 injections and iron infusions. These do not seem to have been deemed urgent or a priority by most GP surgeries and healthcare teams, but many feel these treatments are key to managing their fatigue (a common debilitating symptom of Crohn’s and Colitis) and preventing flares.

¹⁵ Kennedy NA, et al. Frontline Gastroenterology 2020;0:1–8. doi:10.1136/flgastro-2020-101520 <https://fg.bmj.com/content/flgastro/early/2020/06/15/flgastro-2020-101520.full.pdf>

“B12 injection 6 weeks overdue but GPs not doing routine ones - have to have symptoms - pins and needles, tiredness and feeling low.”

Patient with Crohn’s Disease, Wales

2.10 Some routine drug monitoring blood tests have also been delayed or cancelled with 50% (4/8) of services in Wales reducing the frequency of blood monitoring for patients on immunomodulators.¹⁶ Similarly, 54% (193/355) of respondents to our “Life in Lockdown” survey living in Wales reported that they have not been able to access tests and procedures for their Crohn’s or Colitis as usual. Drug monitoring is important to ensure that treatments are being tolerated, with no serious side effects or adverse reactions, and are effective for the individual. While some delay in routine monitoring for stable patients is supported by the British Society of Gastroenterology to reduce unnecessary risks from people coming into hospital, arrangements should be made to ensure these can be carried out as safely as possible.

Delays to planned surgery

2.11 Callers to our helplines have reported that their planned surgery has been cancelled or postponed and it is unclear when their surgery will be rescheduled. The survey of IBD services confirmed that potential elective IBD surgery across all services surveyed had been put on hold¹⁷. This has left people with Crohn’s and Colitis living with pain and difficult symptoms and the awareness that delays to planned surgery may lead to needing emergency surgery, more extensive surgery, life threatening complications or mortality.

“There will be significant delays for those waiting for elective surgery and without doubt this will lead to emergency surgeries for those when the disease progresses during this wait. All surgery and surgical clinics have been cancelled.”

IBD nurse specialist, Wales

3. Information and advice about risk and shielding

3.1 One of the key concerns that have resulted in people contacting our helplines has been confusion about their risk status and whether they should be “shielding”. Some people with Crohn’s or Colitis are classified as high risk according to expert guidance from the British Society of Gastroenterology (BSG)¹⁸, however many did not receive letters from the government or NHS instructing them to shield or did not receive these for some weeks. Without this proof of risk, many vulnerable people were compelled to work by their employers, putting them at even greater risk and causing considerable anxiety.

3.2 Conversely, the NHS sent out blanket shielding letters to patients on certain medications, regardless of what condition they use the medicine for or what dosage they take. This resulted in many people with Crohn’s or Colitis who are at moderate

¹⁶ Ibid, page 4

¹⁷ Kennedy NA, et al. Frontline Gastroenterology 2020;0:1–8. doi:10.1136/flgastro-2020-101520 <https://fg.bmj.com/content/flgastro/early/2020/06/15/flgastro-2020-101520.full.pdf>

¹⁸ <https://www.bsg.org.uk/covid-19-advice/>

risk of complications from coronavirus (as opposed to high risk) incorrectly being told they needed to shield. This has led to people unnecessarily delaying medical appointments and isolating themselves from their friends and family.

- 3.3 We have published patient friendly online decision trees, based on coronavirus risk grids for adults and children and developed by the British Society of Gastroenterology (BSG) and the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN). These risk grids help patients identify their level of risk, share the results with their clinicians and understand how to protect themselves and stay safe and well. Additionally, we supported the rapid development of an IBD Registry risk tool, which enables people to answer a series of questions to identify their risk status¹⁹. To date, 33,000 people with Crohn's or Colitis covered by 167 IBD services across the UK have used the risk tool, including 1,796 people in Wales, of whom 25% are in the high-risk group. In Cardiff, around 20% of the high-risk group were not on the government list. This database offers potential for disseminating critical advice to IBD patients.

"I, like many other IBD nurses, was inundated with calls and emails from patients at the beginning of the pandemic who were anxious regarding their risk associated with underlying conditions and medications and coronavirus. I had to rely on government/public health websites but also reassured patients as per the excellent, specific advice for those with IBD from Crohn's & Colitis UK and British Society of Gastroenterology (BSG). However, soon patients were receiving shielding letters when I had advised that they would be in the moderate risk group. This was not only confusing for patients but also meant that I could have been perceived as misinforming them of their risk. I felt that the advice from Crohn's & Colitis UK and the BSG was much more useful as it was specific to their condition and medication and helped clarify their individual risk rather than a blanket approach that was otherwise being offered."

IBD nurse specialist, Wales

Recommendation:

Clear information and guidance to people about their risk status and the action they need to take to stay safe and well is critical. There needs to be better coordination between the Welsh government/NHS communications and patient charities and specialist clinicians, including the use of registries and improved data-sharing, to avoid the increased risk, anxiety and incorrectly delayed appointments resulting from people receiving the wrong information.

4. Resuming services safely and effectively

- 4.1 As services refocus and resume routine healthcare, it is imperative that decisions about the priorities for dealing with pent-up demand are based on the individual needs of patients. For patients with Crohn's and Colitis, uncontrolled disease activity, delays to planned surgery and delays to diagnosis could lead to a rise in emergency surgery, more extensive surgery, life threatening complications, increased risks of cancer and mortality.

¹⁹ <https://ibdregistry.org.uk/covid-19/>

- 4.2 Priorities should include patients who require urgent care, supporting those with uncontrolled or flaring disease and beginning treatment for people newly diagnosed with Crohn's or Colitis.

Recommendation:

Increased collaboration between primary and secondary care is needed to re-establish referral pathways and drug monitoring and make sure patients do not fall through the gaps. Careful consideration needs to be given to agree the priority for catching up on GP referrals, based on individual patient need.

Recommencing planned surgery is also critical to avoid further pressures on the system and significantly detrimental outcomes for patients. Reintroduction of elective surgery for patients with Crohn's and Colitis is key due to the increased risks of needing emergency surgery, more extensive surgery, life threatening complications or mortality. This should be in dedicated Covid-free sites with segregated staff and testing following clear guidelines from the Association of Coloproctology of Great Britain and Ireland (ACPGBI)²⁰. We would suggest that hybrid "clean areas" with IBD surgery, infusion treatment and diagnostics taking place in one physical site mixed with emergency and infectious disease patients represents an unacceptable risk for patients with Crohn's or Colitis.

"The inevitable deaths and poor outcomes associated with unsafe hospital environments will most likely have large impact and prolonged sequelae with many young patients within the affected group."

Consultant colorectal surgeon, Wales

Recommendation:

We would like to see immediate policy provided by the Welsh Government for Welsh Health Boards that patients with Crohn's and Colitis should have surgery in segregated Covid-free sites within all Health Boards in accordance with guidance from the ACPGBI and Royal College of Surgeons²¹ and access to all treatment in as safe and Covid-free an environment as possible, in which patients will not be at risk of any unnecessary or avoidable infection²².

- 4.3 Increasing access to tests and treatments at home will reduce pressure on services and support earlier diagnosis and more effective monitoring. This includes home faecal calprotectin (FCP) testing, given many laboratories have not been processing stool samples for FCP due to the risk of coronavirus transmission, and ensuring patients can receive subcutaneous medicines at home wherever possible. Subcutaneous biologic drugs are now available, and their access should be widened and expedited, where appropriate.

Recommendation:

Access to home and local testing should be increased and early access to ustekinumab for Ulcerative Colitis (in advance of the 90-day implementation period), and to

²⁰ <https://www.acpgbi.org.uk/news/acpgbi-guidance-on-management-of-patients-with-ibd-requiring-surgical-intervention-during-covid-19/>

²¹ <https://www.rcseng.ac.uk/news-and-events/media-centre/press-releases/rcs-calls-for-covid-free-hospital-sites-to-be-set-up/>

²² <https://www.bsg.org.uk/covid-19-advice/bsg-guidance-on-recommencing-gi-endoscopy-in-the-deceleration-early-recovery-phases-of-the-covid-19-pandemic/>

subcutaneous infliximab and to subcutaneous vedolizumab should be supported, where these are appropriate.

- 4.4 Consideration also needs to be given to the need for mental health support for people with Crohn's and Colitis. People living with Crohn's or Colitis may be twice as likely to experience mental health issues as the general population²³ and these are likely to have been exacerbated during this challenging time. Mental health can also have an impact on physical symptoms. Forty eight percent (171/355) of respondents to our "Life in Lockdown" survey living in Wales reported that their mental health had been negatively impacted as a result of the coronavirus pandemic and lockdown measures.

"I am currently experiencing a flare, but it isn't related to a lack of ability to get my usual medication; it's likely stress."

Patient with Ulcerative Colitis, Wales

"I am struggling with my mental wellbeing and sometimes I do think that the government and the Welsh assembly forgot about us."

Patient with Crohn's Disease, Wales

Recommendation:

Mental health needs should be addressed as part of consultations and support and/or signposting offered as appropriate.

5. Reshaping and refocusing services

- 5.1 IBD services have worked swiftly to remodel care provision during the Covid-19 pandemic with most teams now able to offer care via telephone and video consultations and clinics. Thirty-three per cent (116/355) of the respondents to our "Life in Lockdown" survey living in Wales reported that they had been offered virtual appointments during the coronavirus pandemic.
- 5.2 Greater use of technology and remote care reduces the risks of potential infection and ensures that those who are too anxious to attend hospital are supported. There is potential to utilise interpreters for those with no or limited proficiency in English or Welsh and who may have more limited access to healthcare as a result, for example, from black, Asian and minority ethnic (BAME) communities. It can also be managed more flexibly in areas where there is currently limited or no IBD nurse provision, as is the case in some services in Wales²⁴.
- 5.4 Virtual clinics are welcomed by many patients in terms of convenience, reduced travel and associated costs and this is particularly true for some patients with Crohn's or Colitis due to the nature of the symptoms which often make journeys outside of the home difficult. However, it is unlikely to be appropriate for all situations, where face-to-face interaction or examination would be beneficial. Fifty-two per cent (186/355) of respondents to our "Life in Lockdown" survey living in

²³ <https://crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/mental-wellbeing>, Mikocka-Walus A, et al. Therapy with antidepressants for the management of inflammatory bowel disease. Cochrane Database Syst Rev. 2019 Apr 12;4(4) www.ncbi.nlm.nih.gov/pmc/articles/PMC6459769/

²⁴ Local IBD Benchmarking Reports, www.ibduk.org

Wales reported that they would like to have the choice of remote or face-to-face appointments when the pandemic ends. Sixteen per cent (58/355) expressed a preference for having appointments remotely where possible when the pandemic ends. However, 24% (86/355) reported a preference for appointments in person. We hope to see increased options for patients on how they receive their care in the future, including virtual clinics when appropriate, with discussion of the options available. It is important that care delivered virtually is personalised and considers the whole person, rather than being focussed solely on medical treatment.

“Looking at video consultation etc, I am very much in support of if it enables a more effective way of delivering results but I’m also conscious that this would only be suitable for certain situations and some would prefer a face to face meeting.”

Patient with Crohn’s Disease, Wales

“My care is 20 miles away in a city centre so it can take up a lot of time travelling in heavy traffic and struggling to park. I would only want to receive this kind of appointment if my condition is stable, there would need to be an option for a face to face consultation if I had concerns or was deteriorating - or at least opportunity for a swift follow up post telephone/video appointment. I have had one telephone appointment and it was a really good experience. It was not a consultant I know but it was thorough and there was plenty of opportunity for me to input and ask questions. The one issue was the need for me to have my bloods monitored which would normally happen in clinic. However, this has been arranged to take place at my GP surgery instead which is great.”

Patient with Crohn’s Disease, Wales

“There have been difficulties when using the telephone review with those newly diagnosed as it is very difficult to reassure someone and discuss the implications of a diagnosis of IBD in this way. Telephone reviews are also much easier when a relationship has already been established and you know a person well.”

IBD nurse specialist, Wales

- 5.5 Empowering patients and supporting self-management will also be important as services work to reduce backlogs. These are key elements of the 2019 IBD Standards²⁵ which define high quality care and were developed by IBD UK, an alliance of 17 patient and professional organisations, which is chaired by Crohn’s & Colitis UK and includes the British Society of Gastroenterology, Royal College of Nursing and Royal College of GPs. This work is being driven in Wales by IBD Wales, a group of leading gastroenterologists, colorectal surgeons, clinical nurse specialists, dietitians and patients.

Recommendation:

Patients should be involved in discussions with clinical teams about service delivery and any changes to this to ensure that this meets their needs. Consideration should be given to the 2019 IBD Standards to ensure safe, consistent, personalised, high quality care.

²⁵ www.ibduk.org/ibd-standards, Consensus standards of healthcare for adults and children with inflammatory bowel disease in the UK, Kapasi et al, 2019 <https://fg.bmj.com/content/11/3/178>

- 5.6 Before Covid-19, the NHS Wales Health Collaborative had agreed to appoint an IBD Clinical Lead for Wales. It is important that this continues, especially in view of current challenges. Additionally, this is a valuable opportunity to conduct a one-day inquiry into IBD service provision, with IBD Wales and the new IBD Clinical Lead for Wales ideally placed to take forward any recommendations arising from this.

6. Access to toilets

- 6.1 During such a challenging time, being able to go outside is important for people's mental and physical wellbeing, particularly for those who have been shielding and in isolation. However, the lack of access to toilets - including public and accessible toilets and those in supermarkets, shopping centres, pubs and restaurants - are preventing people with Crohn's and Colitis from meeting friends and family, going outside to exercise, pick up their medication or shop for food for fear of having an accident in public, due to the need to access a toilet within minutes.
- 6.2 The lack of public and accessible toilets is depriving the most vulnerable people in society of the simplest freedoms, heightening their isolation at a time when staying connected and healthy is harder than ever before. Fifty-nine per cent (209/355) of respondents to our "Life in Lockdown" survey living in Wales reported that they were concerned about leaving the house due to public toilet closures, while 45% (160/356) reported feeling isolated from other people.

"I have been shielding so I'm very anxious of where Wales will go with advice to those shielding. Public toilets here are all too few already and the thought of going out is too risky ordinarily so the impact is so much more compounded in these times. Accessibility to toilets are what I would assume non-existent to all let alone those with needs. It's a scary prospect. So at the moment for me, staying home is the only option for now."

Patient with Ulcerative Colitis, Wales

"Because all the public toilets have been closed it has been impossible to go out. I live in a coastal semi-rural area where one has to drive to access shops etc. I could not get delivery slots and have not been able to access toilets when I had to go out. I am appalled that the local council have been so mean as to close public toilets and therefore condemn some of us to isolation and unable to access local beaches for a flat walk for fear of being caught short. The toilet situation has been the biggest problem for me."

Patient with Microscopic Colitis, Wales

Recommendation:

Public and accessible toilets - and those in supermarkets, shopping centres, pubs and restaurants - should be reopened, supported by clear guidance for safety and hygiene from the Welsh Government, in line with the principles and duties set out in the Public Health (Wales) Act 2017.

7. Conclusion

- 7.1 The Covid-19 outbreak and its management has had a significant impact on the healthcare of people with Crohn's and Colitis in Wales. This will have implications

for some time to come and it is important that services are now resumed, under safe and appropriate conditions, including Covid-free hospitals for surgery, with appropriate prioritisation based on individual need. Clear plans need to be put into place to ensure continuous service delivery in the future.

- 7.2 There are opportunities to be harnessed through greater use of technology and remote care and home and point-of-care testing, and patients should be involved in discussions about refocusing and reshaping services. Treatment and care should be provided in line with the 2019 IBD Standards to ensure it is consistent, safe, high quality and personalised.
- 7.3 Crohn's & Colitis UK is a member of IBD Wales, an alliance which brings together all relevant stakeholders across the multidisciplinary team, including patients, and will work collaboratively with the new IBD Clinical Lead and other stakeholders to deliver the recommendations contained in this submission. Members of IBD Wales would also very much welcome further involvement with the Health, Social Care and Sport Committee to look in more detail at IBD services in Wales and the unique opportunities that exist post-Covid for improving these services in line with the IBD Standards.