Scottish Government Consultation: Long Term Conditions Framework

Crohn’s & Colitis UK Submission

1. **Do you agree that Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work?**

1.1. Yes.

1.2. A cross-cutting approach, combined with condition-specific work, could lead to a more effective use of resources and better patient care and outcomes. With one in four Scots living with more than one long-term condition, a holistic, whole-person approach to care with cross-condition support alongside condition-specific work could better address their needs than wholly isolated strategies for each condition.

1.3. We must acknowledge the unique characteristics of specific conditions and recognise that condition-specific work remains vital to quality patient care. At the same time, by embracing cross-cutting approaches in some areas, we can maximise resource efficiency and improve patient outcomes by addressing more of their cross-departmental needs. Many individuals living with long-term conditions, such as Crohn’s disease and Ulcerative colitis, the two most common forms of Inflammatory Bowel Disease (IBD), often experience multiple co-morbidities that do not neatly fit into separate clinical categories. Several symptoms and experiences overlap across different conditions, which means that they could be tackled similarly if cross-cutting improvement initiatives are implemented.

1.4. Despite substantial evidence linking conditions such as IBD to rheumatological diseases, management of these conditions remains fragmented. This siloed approach results in detrimental outcomes for patients, forcing them to endure prolonged delays, often spanning years, before receiving a diagnosis for co-morbidities. We heard from one patient who lives with Crohn’s Disease and extra intestinal manifestations of IBD, which affect 50% of people living with the conditions.[1] They shared that it took 10 years to be diagnosed with Axial Spondyloarthritis (the most common extraintestinal manifestation in those with IBD), which is an incurable inflammatory spinal disease, and Uveitis, which is an inflammatory eye condition.[2] These conditions are known co-morbidities of IBD, however, due to siloed working practices and a lack of awareness of the signs and symptoms, it often takes up to a decade to receive a diagnosis.[3] A collaborative approach between teams in gastroenterology and rheumatology, where co-morbidities are common, could help

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[1] Harbord M, Annese V, Vavricka SR, et al. The first European evidence-based consensus on extra-intestinal manifestations in inflammatory bowel disease. J Crohns Colitis 2016;10:239–254.

[2] Gionchetti P, Calabrese C, Rizzello F. Inflammatory bowel diseases and spondyloarthropathies. *J Rheumatol Suppl*. 2015;93:21-23. doi:10.3899/jrheum.150628

[3] Troncoso LL, Biancardi AL, de Moraes HV Jr, Zaltman C. Ophthalmic manifestations in patients with inflammatory bowel disease: A review. World J Gastroenterol. 2017 Aug 28;23(32). Available here: Ophthalmic manifestations in patients with inflammatory bowel disease: A review - PMC

prevent such delays in diagnosis in the future. By ensuring that patients presenting with symptoms are assessed more quickly for conditions like Axial Spondyloarthritis, and the practice of cross-cutting approaches to manage these conditions, we can ensure earlier diagnosis of co-morbidities and the provision of greater support, thereby improving patient care and outcomes.

1.5. One way a cross-cutting approach could operate is by focusing on the treatment and management of key overlapping symptoms such as fatigue. People living with Crohn's and Colitis commonly experience fatigue. During a flare-up, fatigue affects around 7 in 10 [4] people with Crohn's and Colitis, and during remission around 4 in 10 people experience it.[5] Fatigue can have a significant impact on a person's quality of life, social life, family life, education and career.

1.6. We know that fatigue is a key symptom of several other conditions such as ME/CFS, MS, rheumatoid arthritis, and diabetes. Wider access to occupational therapy for fatigue, and more generally, fatigue-specific support and treatment within communities through a cross-cutting approach could therefore be a better and more efficient use of resources, enabling people with a number of long-term conditions to better manage their symptoms closer to home.

2. Are there any improvements in prevention, care or support you have seen in a long-term condition you have, or provide care and support for, that would benefit people with other long-term conditions?

2.1. Crohn's & Colitis UK have worked with Sheffield Teaching Hospitals NHS Foundation Trust, the University of Sheffield, epiGenesys, Sheffield Microsystems Coaching Academy and VoiceAbility to deliver a three-year project under a new Health Foundation programme called Common Ambition. The project aimed to redesign IBD services, guided by Patient Coach Sam McCormick, so that services were shaped by those who use them, their families and carers. As a result, the AWARE-IBD team co-designed and used a novel measure of patient experience, a toolkit to support patients in consultations, a personalised care plan, an education programme, and made changes to nurse and consultant clinics. The project evaluation concluded that putting patients in control of their care improved patient experience significantly overall.

2.2. The top five recommendations from the project for other IBD services across the UK are:

- Aim to understand what matters to people with IBD and ensure personalised care, good communication and access.
- Measure and embed patient experience.
- Listen to underserved patient groups in a meaningful way that acknowledges needs, preferences and values, and addresses barriers.
- Form partnership with relevant stakeholders with a shared goal of improvement.

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[4] Fatigue and IBD

[5] Crohn's & Colitis UK (2014) Tackling Challenges in IBD Fatigue Report 2014. www.fatigueinibd.co.uk/wp-content/uploads/2017/11/Tackling-Challenges-in-IBD-Fatigue-2014-report.pdf

- Co-design service changes with people with lived experience, led by patient priorities.

2.3. The insight and recommendations from this project are all about giving patients more autonomy in their care, and they should certainly be considered for other long-term conditions to improve patient experience.

3. Do you have any thoughts about how areas for condition-specific work should be selected? This means work which is very specific to a health condition or group of health conditions, rather than across conditions

3.1. When selecting condition-specific work, it is important to consider the complexity of different conditions, and the level of specialised support required. Factors such as the rates of late diagnosis and their impact on patient outcomes like disease progression, functional status (including daily living activities), quality of life, adverse events (such as the need for emergency surgery), and mortality rates should also be considered.

3.2. Diagnosis of Crohn's and Colitis is taking years, when it should take weeks. Among people with a diagnosis of Crohn's or Colitis, the average time between having a misdiagnosis of irritable bowel syndrome (IBS) and receiving a diagnosis of IBD is 5.5 years.[6] People who experience the longest delays in diagnosis are four times more likely to have serious bowel complications and twice as likely to have surgery.[7]

3.3. Delays to treatment narrow treatment options and can lead to disease progression and result in avoidable emergency admissions that place unnecessary pressure on already overstretched A&E departments. This situation not only raises costs for NHS Scotland but also significantly affects patient outcomes. More patients are likely to experience debilitating symptoms due to disease progression, which can harm their quality of life. This can prevent them from participating in education and work, and increase their risk of requiring emergency surgery, which may be life-threatening. Such outcomes must be considered when assessing where condition-specific support is needed.

3.4. Crohn's and Colitis are complex and unpredictable diseases to manage that require significant specialist support. Unlike some other long-term conditions, Crohn's and Colitis cannot be managed safely by GPs alone. Whilst Crohn's & Colitis UK partnered with the Scottish Government Modern Outpatient Programme to co-produce a patient flare card which helps people to recognise the signs of a flare and try to manage it with some initial steps such as dose escalation for some medications, most patients will not respond to this initial treatment. Since every patient will respond differently to treatments and the complexity of individual cases, most patients will need support and further guidance from an IBD Nurse Specialist during a flare. Such support enables patients to access timely information, advice, and treatment, such as by allowing existing medications to be safely adjusted, and timely referral to secondary care where necessary. This support provided by IBD nurses helps IBD patients get their

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[6] Crohn's & Colitis UK (2022), Epidemiology summary: Incidence and Prevalence of IBD in the UK.

[7] NIHR, Delayed diagnosis of inflammatory bowel disease is linked to worse clinical outcomes. Available at: Delayed diagnosis of inflammatory bowel disease is linked to worse clinical

flares under control more quickly, helping to prevent further disease progression and costly interventions like hospitalisation and A&E admission. **Conditions such as Crohn's and Colitis that require higher levels of specialist support, usually outside of primary care, should therefore be considered as areas where condition-specific work is required alongside cross-cutting approaches.**

4. What would help people with a long term condition find relevant information and services more easily?

4.1. The Government's plan should include partnership with charities that provide self-management support and services, so that helpful information and resources can be accessed more easily. We often hear from patients about the psychological distress and feeling of hopelessness they experience whilst on waiting lists for investigations and treatment. For many the wait means further deterioration of their condition(s), with far-reaching implications. This applies to all conditions but is especially tough for people experiencing physical pain or ill-mental health, as is the case for most people waiting to be diagnosed with IBD.

4.2. Self-management support needs to be co-designed with patients and delivered in a way that suits them. This could be written, visual, on-line information on how to manage symptoms and prepare for the appointment or procedure. Partnering with charities to provide self-management support and services could include advice and information on pain relief and psychological support to deal with pain, routine monitoring during the waiting time and interim interventions and treatments as required, adequate specialist advice capacity and clear pathways to specialist advice if symptoms escalate.

4.3. Currently multiple disease awareness campaigns linked to a symptom checker are run by charities to address patient-led barriers to early diagnosis. This includes gastro-intestinal conditions such as IBS, IBD, coeliac disease, and bowel cancer. NHS Scotland should partner with patient charities to bring together intelligence and build a single symptom checker integrated with NHS 24, A&E and app services to centralise the information for patients and healthcare professionals, so it is easier to access.

5. What would help people to access care and support for long term conditions more easily?

5.1. Crohn's and Colitis are complex diseases to manage that require specialist support. The availability of IBD Nurse Specialists across Scotland is vital for people living with IBD to be able to access responsive health services and improved clinical outcomes, and many patients describe them as their 'lifeline'.[8] This is especially true as GPs are not specialists and cannot provide the same level of information and support, so the timely information and advice provided by IBD nurses can prevent costly interventions like hospitalisation and A&E admission.

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[8] IBD UK 2024. Crohn's and Colitis Care in Scotland: A Vision for Change, page 8. Available at: IBD-Devolved-Nations-Report_Scotland_Final.pdf

5.2. Where people living with IBD report having contact with an IBD Nurse Specialist, they are also more likely to have the information and skills to manage their condition. However, despite the vital service IBD nurse specialists provide, a recent audit found that 1 in 3 IBD services in Scotland are not meeting safe staffing requirements for nurses, threatening patient outcomes and putting lives at risk. [9] This needs to change urgently if we want to see improvements in care for people living with IBD, a reduction in emergency surgeries and A&E admissions, and lower costs for NHS Scotland.

5.3. IBD nurse advice lines are also overwhelmed, with roughly 1 in 4 people living with IBD in Scotland reporting not receiving a response within 48 hours of contacting a helpline for advice when experiencing a flare, despite the IBD standards stating that a response should be received by the end of the next working day.[10]

5.4. Recruiting and retaining appropriately trained IBD Nurse Specialists is crucial in providing and maintaining high quality care. Expanding the workforce of IBD nurses could reduce emergency admissions, improve primary care management, and enhance patient wellbeing and self-management. Therefore, the number of IBD nurses must be increased in line with service standards so patients can be supported to stay well in the community, with referrals to secondary care initiated when appropriate.

5.5. **We would like to see an expansion of the specialist nursing workforce through the introduction of a national specialist nursing plan including IBD Nurse Specialists as part of the Long-Term Conditions Framework.** A national specialist nursing plan would not only support people living with Crohn's and Colitis but would also mean that people with other conditions such as Parkinson's are able to access essential specialist nurses, improving quality of care and access to care for people with a number of long-term conditions, as well as increasing their ability to manage their conditions closer to home, and reducing pressure on emergency services.

6. How could the sharing of health information/data between medical professionals be improved?

6.1. Poor communication and outdated IT systems are not just inefficiencies in the NHS; they are actively harming patient care. Communication between IBD services and people with IBD, as well as within IBD services and between primary and secondary care, remains a crucial area for improvement. IBD services that can communicate effectively with service users can enhance people's understanding and confidence with managing their condition, empowering them to make informed healthcare decisions.

6.2. The 2024 IBD UK service audits found that communication and access were rated as the most important aspect of care by people living with IBD. Respondents emphasised that people with IBD want to be seen quickly, for it to be simple and convenient for them

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[9] IBD UK 2024. Crohn's and Colitis Care in Scotland: A Vision for Change, page 8. Available at: IBD-Devolved-Nations-Report_Scotland_Final.pdf

[10] *Ibid.*, page 5.

to contact their IBD service and that they value communication that is rapid and easy to understand. Despite this, almost half of adults living with IBD in Scotland feel their care is not well coordinated between their GP and IBD team.[11] We need IT systems to talk to each other; the lack of shared electronic patient records is a critical barrier to coordinated care.

6.3. A lack of shared records is also negatively impacting pandemic preparedness. The IBD Risk Tool used by over 40,000 people across the UK with IBD identified 26% of users as Clinically Extremely Vulnerable and 40% as Clinically Vulnerable or moderate risk. In a paper published in the Lancet, the tool demonstrated that patient-generated data can facilitate rapid risk stratification with respect to Covid-19 and compensate for deficiencies in hospital data.

6.4. Despite this emerging evidence, we saw a lack of recognition in public and clinical communications during the Covid-19 pandemic that people with Crohn's and Colitis could fall into the category of Clinically Extremely Vulnerable (priority group 4) and Clinically Vulnerable/moderate risk (priority group 6). As a result of this lack of clarification, 1 in 5 people with Crohn's and Colitis did not receive the correct shielding information.

6.5. For those who did not receive a shielding letter, this exposed them to unnecessary risk and was a barrier to accessing vital support. Those who wrongly received a letter have told us that shielding negatively impacted their mental well-being and employment. Without this proof of risk, many vulnerable people were compelled into attending work by their employers, putting them at even greater risk. Accuracy of shielding letters was challenging especially for those who were newly diagnosed, those who had their medication changed or those who are flaring.

6.6. **To address this issue, there needs to be greater integration of primary and secondary care through electronic methods of communication (such as emails rather than letters) and technological innovation initiatives such as linked databases.**

7. What services outside of medical care do you think are helpful in managing long term condition(s)? You may wish to comment on how these services prevent condition(s) from getting worse.

7.1. Toilet access

Access to public toilets is crucial for managing day to day life with Crohn's or Colitis. People living with Crohn's or Colitis often suffer from an unpredictable and urgent need to use a toilet; as many as 3 in 4 people with the conditions have experienced bowel incontinence.[12] Without access to facilities, they face the risk of embarrassing accidents, which can lead to anxiety, isolation, and discrimination. Therefore, quick

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[11] IBD UK 2024. Crohn's and Colitis Care in Scotland: A Vision for Change, page 7. Available at: IBD-Devolved-Nations-Report_Scotland_Final.pdf

[12] Crohn's & Colitis UK November 2021. Position Statement: Access to Toilets, page 2. Available from: ACCESS TO TOILETS

access to suitable toilet facilities is crucial, either to prevent or act should an accident occur.

7.2. Transport

Access to public transport is vital for people with long-term conditions to be able to get around, and particularly to be able to travel to medical appointments. Especially for people living in rural areas, accessible public transport is extremely important in being able to make a longer journey to hospital appointments, which in some cases, could be 90-120 miles away.

7.3. Flexible working hours and reasonable adjustments

Workplaces that accommodate flexible working hours and remote working, make reasonable adjustments where required, and have an understanding of long-term conditions such as Crohn's and Colitis and their unpredictable nature, help to remove barriers to accessing work for people living with the conditions.

Flexible working hours such as a later start can help people with Crohn's and Colitis if their bowels are more active in the morning, as is often the case. During flare-ups, there may also be times when shorter working hours or working from home would be helpful.

Additional meal or snack breaks can also be useful for people living with Crohn's or Colitis. Many people with IBD have difficult eating a regular-sized meal, so they may need to eat smaller meals more often. Breaks may also be helpful if the individual takes prescribed medication at certain times of the day.

7.4. Adult disability payment (ADP)

Adult disability is a payment to help people who have a disability or long-term health condition that affects their everyday life. People living with Crohn's or Colitis may worry about the extra costs it can bring, such as prescriptions and higher household bills. Being granted ADP can therefore significantly help people living with IBD to manage to higher costs they may face because of their condition.

8. What barriers, if any, do you think people face accessing these (non-medical) services?

8.1. Toilet access

Many public spaces and businesses do not provide toilets for non-customers, and existing facilities often suffer from issues with privacy, cleanliness and accessibility. In some cases, people with IBD are even denied access to employee or customer-only toilets despite having a legitimate medical need.

We know that 9 in 10 people with Crohn's and Colitis plan their activities based on toilet access.[13] It is challenging, stressful and isolating if public and accessible toilets are not available. The dwindling number of public toilets across Scotland means many people living with Crohn's and Colitis cannot comfortably leave their homes and are prevented from engaging in everyday activities such as shopping, traveling, working, and socialising.

Even when there are accessible public toilets, people with Crohn's and Colitis frequently experience discrimination trying to use them. 1 in 2 people with Crohn's or Colitis report having experienced discrimination for using an accessible toilet, with over 60% of these instances including either verbal and or physical abuse.[14] Such discrimination is often due to a lack of awareness of invisible conditions such as Crohn's and Colitis, which is why 'Not Every Disability is Visible' signage and other awareness raising initiatives are vital to ensuring people with invisible conditions can access these facilities when they need them.

The constant worry of having an accident in public because of a lack of accessible toilet facilities can lead to heightened anxiety, avoidance of social situations, and, in extreme cases, complete social isolation, pushing people out of education and work.

We call on national and local decision makers to:

- **Take urgent action to improve access to toilets**. Local authorities and transport bodies must work with communities to plan, fund, and maintain accessible public toilets: with clear, up-to-date information on where and how to access them. Everyone should be able to find a clean, safe toilet when they need one.
- **Ensure public toilets and transport hubs display 'Not Every Disability is Visible'** signage. All accessible toilets, whether in private or public buildings, should recognise that not all conditions and disabilities are visible and display Not Every Disability is Visible signage.
- **Encourage more businesses to recognise Can't Wait Cards**, so that people with Crohn's or Colitis are able to access toilets that are not always open to public in shops, restaurants, and at work.

8.2. Transport

Despite the importance of public transport, the amount of live registered bus routes has plummeted by 44% in Scotland since 2006, according to Scottish Labour, with more than 1,400 routes lost since then.[15] People living within rural communities who are unable to drive risk being 'cut off' from key services such as hospitals and medical practices as a result.

We heard from one member of our community, who is living with Colitis in South West Scotland. They rely on local bus services to travel 90 miles to Dumfries and Galloway Hospital, as they can no longer drive, and do not have anyone to drive them to

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[13] Crohn's & Colitis UK Position Statement, November 2021. Available here: ACCESS TO TOILETS

[14] Not Every Disability Is Visible campaign history

[15] Areas risk being 'cut off' after bus routes plummet 44% since 2006 – Labour | STV News

appointments. They raised concerns about how they will be able to travel to hospital appointments now that all but two of Stagecoach's bus services in Dumfries and Galloway will be dropped in August.

Even when public transport is available, access to toilets is often inadequate. While trains typically have toilets, there is usually only one or two available, and they frequently are out of order. Additionally, information about the location of these toilets and their operational status is not always clearly displayed. It is often unclear whether there are toilets at the station, what their opening hours are, if they are free to use or located behind a ticket barrier, and whether an accessible toilet is available. There must be accessible public toilets either on the transport or at the stations, along with clear signage on maps and at the stations indicating where these toilets are located.

We call on national and local decision makers to:

- Ensure public transport routes continue to operate to prevent communities from being cut off from key services by:
    - Exploring alternative transport partnerships, even temporarily, to ensure bus services can continue to operate in the short-term whilst long-term solutions are examined.
    - Exploring the creation of municipal bus companies to secure long-term resilience.
- Communicate clearly with local communities about any changes to operating bus routes so they can plan travel efficiently.
- Assure that open toilet facilities will be available on trains, with clearly displayed signage to indicate where toilets are located; notify passengers prior to their journey if toilet facilities are out of order.
- Ensure the provision of free, accessible toilets at train and bus stations, with clear information about open hours and location, including if they are located behind a ticket barrier, so people with IBD can plan their journeys more effectively.

8.3. Flexible working and reasonable adjustments

Whilst many workplaces provide flexible working arrangements to support those with families, such as an earlier finish to accommodate pick-up, the same flexibility is not always afforded to people living with fluctuating long-term conditions such as IBD. Flexible working such as adaptable hours and optional remote working can be a game-changer for people living with long-term conditions, allowing them to continue to deliver at work whilst dealing with often challenging symptoms. When such measures and reasonable adjustments are not provided to people with long-term conditions, they will often end up having to take a lot of time off work, miss deadlines, and in some cases, stop working completely. This not only affects a person's career progression and earning potential, but adds to the isolation, stress, and anxiety they already have to deal with living with the conditions.

We call on the Government and Employers to:

- **Champion and promote flexible working across Scotland.** Now that requesting flexible working is a day-one right in UK law, the Scottish Government should work with employers, trade unions and disability organisations to embed flexible working practices, especially for people with fluctuating conditions like IBD.
- **Prioritise and implement training on invisible disabilities for all employees.** Ensure training on invisible and fluctuating conditions like Crohn's and Colitis, endorsed by the Fair Work Convention, is included in basic training for all employees.
- **Trial phased return and partial sick leave models.** Work with NHS Scotland and public sector employers to trial and promote flexible return-to-work models, including 'partial sick leave', for those with relapsing-remitting conditions.
- **Launch and fund a national awareness campaign co-designed with patients** on invisible and fluctuating conditions, working with charities and disabled people's organisations to reduce stigma in the workplace and wider society

8.4. Adult disability payment (ADP)

Despite the fact people with Crohn's and Colitis have a long-term condition that affects their everyday lives, and therefore many should qualify for ADP, very few are in receipt of this payment. One particular area that affects a number of people living with the conditions is incontinence, with 9 in 10 people with IBD reporting planning journeys based on access to toilets.[16]

The current descriptors for toilet needs and incontinence are not fit for purpose. The ADP guidance states:

"Daily living component 5 considers a claimant's ability to get on and off the toilet, to manage evacuation of the bladder and/or bowel and to clean afterwards. This activity does not consider the ability to manage clothing, climb stairs or mobilise to the toilet."

The guidance as currently written frames incontinence in very limited terms. Points are awarded based on the need for assistance and aids. This is a reductionist view of the wide range of toilet needs that exist and impact on individuals in our society, serving to exclude significant numbers of people who live with debilitating bowel conditions or symptoms. The descriptors and guidance fail to recognise the differences between types of toilets needs, including frequency of bowel movement, urgency, and incontinence. Each can have a distinct impact on people living with Crohn's and Colitis, and their independence and participation.

We believe the social security system should be simple, fair, and properly support those living with long-term, fluctuating conditions such as Crohn's and Colitis. Health assessments for disability benefits should be designed to capture the unique experiences of someone living with Crohn's or Colitis and should properly accommodate for symptoms that fluctuate.

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[16] ACCESS TO TOILETS

We therefore recommend that the toilet needs, and incontinence descriptor and criteria are reviewed with input from people with lived experience and updated.

We believe that this element of the ADP assessment should recognise:

- The impact on a person’s ability to manage toilet needs safely, reliably, repeatedly and in a timely manner.
- The loss of independence caused by the urgent or frequent need to access a toilet, and the risk of accidents if support or facilities are not immediately available.
- The fatigue and dehydration resulting from multiple bowel movements per day, active disease, or the physiological impact.
- Disrupted sleep, caused by having to wake several times during the night to use the toilet or from experiencing accidents while asleep.
- Psychological distress, including anxiety and social isolation, arising from the fear of incontinence in public or while travelling, and the difficulty of managing stoma bags discreetly.
- The support needs many individuals have from carers, family or partner, including assistance with personal care, dressing, washing soiled clothes and bedding, or cleaning affected rooms and bathrooms.
- That managing a stoma (e.g. a colostomy or ileostomy bag) does not remove all support needs. People may still experience leaks, skin issues, urgency, particularly during active disease.
- The significant barriers to employment posed by unpredictable urgency or incontinence, even in workplaces that offer flexible or remote working arrangements.
- The impact on a person’s ability to travel to and from work, attend appointments, or use public transport safely and confidently.
- While reasonable adjustments are vital, it is often not realistic or dignified for someone to work (even from home) while experiencing severe urgency, frequent episodes, or uncontrollable bowel symptoms.

9. What should we know about the challenges of managing one or more long term conditions?

9.1. Mental health challenges can be a major part of living with Crohn’s or Colitis. Research suggests that people living with Crohn’s or Colitis may be twice as likely to experience mental health problems, like anxiety and depression, as the general population.[17] And around half of all people with the Crohn’s or Colitis say it has affected their mental health in some way.[18]

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[17] Mental health and wellbeing with Crohn's or Colitis

[18] *Ibid.*

9.2. Living with a long-term condition like Crohn's or Colitis can trigger lots of different feelings and emotions. People living with IBD often feel shocked or a sense of disbelief when they are first diagnosed and find it hard to adjust. They might also feel anxious, frustrated, sad, scared, or angry about having the condition and dealing with distressing symptoms. Not knowing what might happen in the future can make people living with IBD feel helpless and uncertain. They may feel very isolated or even ashamed about their condition.

9.3. Symptoms like diarrhoea, pain and fatigue can limit how much people living with Crohn's or Colitis can go out with friends and family, which can increase isolation. This can be hard for others to understand when symptoms are not visible, and resulting feelings can increase the risk of depression or anxiety.

9.4. Despite the severe impact living with long-term conditions like Crohn's and Colitis can have on mental health, a recent IBD UK survey found that only half (53%) of Scottish IBD services agreed that people with IBD are routinely asked about their mental health at outpatient appointments and reviews, and no services reported having a policy in place for investigating and treating people living with IBD who are also struggling with their mental health.[19] Mirroring these results, only 1 in 5 (21%) people with IBD agreed that they were asked about their mental health, and treatment options to manage this.[20]

9.5. There needs to be greater recognition of the impact living with one or more long-term conditions can have on a person's mental health. Mental health support for people with long-term conditions should therefore be a key aspect of the cross-cutting approach of the Long-Term Conditions Framework. Whilst we would like to see mental health support integrated throughout IBD services, no adult IBD service in Scotland currently has a psychologist regularly available within the MDT, making it difficult to provide much needed mental health support. As a result, we welcome a cross-cutting approach to addressing this gap in psychological support.

9.6. **Local mental health support services should be established to specifically support those struggling with their mental health as a result of living with one or more long-term conditions.** This initiative will enable individuals living with long-term conditions to access crucial psychological support within their communities. With services like talking therapy and essential coping tools, they will be better equipped to manage their mental health. Ultimately, this will lead to a significant improvement in quality of life for countless individuals living with long-term conditions, reducing isolation and keeping them in work and education.

10. What would strengthen good communication and relationships between professionals who provide care and support and people with long-term condition(s)?

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[19] IBD-Devolved-Nations-Report_Scotland_Final.pdf

[20] *Ibid.*

10.1. Better communication between healthcare professionals and people with long-term conditions such as Crohn's and Colitis can help to strengthen relationships and increase trust in healthcare professionals to provide quality care.

10.2. Through shared decision making, people living with long-term conditions can be actively involved in decisions about their care. Throughout the treatment process, the IBD Standards emphasise that people should be supplied with adequate information on the risks and benefits associated with medical and surgical interventions, to contribute to shared decision making.

10.3. A significant number of patients do not have access to essential information, which impedes their ability to make choices that align with their lifestyles. For instance, some IBD patients may find self-administered injections to be more suitable than infusions, and shared decision making allows them to communicate this preference. In the absence of meaningful information, the effectiveness of shared decision-making diminishes, failing to enhance patient experiences and outcomes.

10.4. Individuals who demonstrate increased knowledge, skills, and confidence in managing their health are generally more inclined to participate in decisions about their care, which can contribute to increased patient satisfaction and improved outcomes.[21] **We therefore urge health boards and hospitals to support patients in accessing and using the comprehensive resources available to support shared decision making including written information, peer support, counselling, decision-making aids and education opportunities. It is vital to empower patients with the knowledge they need to make informed decisions about their care.**

11. What digital tools or resources provide support to people with long term conditions?

12. What new digital tools or resources do you think are needed to support people with long term conditions?

13. How do you think long term conditions can be detected earlier more easily?

13.1. Primary care diagnostic pathway for lower gastrointestinal symptoms

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[21] IBD UK 2021. Crohn's and Colitis Care in the UK: The hidden cost and a vision for change. Available at: https://crohnsandcolitis.org.uk/our-work/campaigns/improvingyour-healthcare/ibd-uk-and-the-ibd-standards/crohn-s-and-colitis-care-in-the-ukthe-hidden-cost-and-a-vision-for-change. Last accessed: April 2024.

Diagnosis of Crohn's or Colitis is taking years, where it should take weeks.[22] People who experience the longest delays in diagnosis are four times more likely to have serious bowel complications and twice as likely to have surgery.[23] Delays to treatment narrow treatment options and can lead to disease progression and result in avoidable emergency admissions that place unnecessary pressure on already overstretched A&E departments. This not only has a negative impact on patient outcomes but can affect people's ability to continue in education and work.[24]

The lack of a clear patient-led diagnostic pathway in primary care for lower gastrointestinal conditions means people are not able to access the right tests at the right time.[25] The latest service audit carried out by IBD UK in Scotland shows that over 3 in 5 (65%) adults reported waiting more than 4 weeks to be referred from primary care to a specialist and nearly a quarter (22%) were diagnosed over 6 months after being referred.[26] For patients to reach the right services as quickly as possible, it is essential that they have access to information to support them to advocate for the right test at the right time, and that primary healthcare professionals are aware of the signs and symptoms of Crohn's and Colitis and the correct tests to ask for.

In 2023, we worked with the Scottish Government on a campaign to raise awareness of signs and symptoms of Crohn's and Colitis, urging anyone concerned to visit their GP.[27] To make a real impact going forward we need a nationally agreed pathway for the diagnosis of people presenting with lower gastrointestinal (GI) symptoms.

Information we obtained under Freedom of Information Act in 2023 revealed that faecal calprotectin tests are not available in primary care in around 30% of Scottish Health Boards. Whist we are working with the Centre for Sustainable Delivery (CfSD) to implement the national primary care diagnostic pathway for lower gastrointestinal symptoms, which includes use of faecal calprotectin as an investigation for possible IBD, and it is currently going through the approval process, we also need the Scottish Government to work with Health Boards to secure access to faecal calprotectin tests across Scotland to improve early diagnosis for IBD and reduce costs for the NHS.

Long waiting times for endoscopy are also contributing to delays in diagnosis. Data from Public Health Scotland shows that, in January 2025, almost 16% of patients waited over a year for a colonoscopy, which is the greatest proportion since August 2022.[28]

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[22] IBD UK 2024. Crohn's and Colitis Care in Scotland: A Vision for Change, page 3. Available at: IBD-Devolved-Nations-Report_Scotland_Final.pdf

[23] NIHR, Delayed diagnosis of inflammatory bowel disease is linked to worse clinical outcomes. Available at: Delayed diagnosis of inflammatory bowel disease is linked to worse clinical

[24] *Ibid.*

[25] https://www.birmingham.ac.uk/news/2024/new-inflammatory-bowel-disease-testing-protocol-could-speed-up-diagnosis

[26] IBD UK 2024. Crohn's and Colitis Care in Scotland: A Vision for Change, page 3. Available at: IBD-Devolved-Nations-Report_Scotland_Final.pdf

[27] Scottish Government (2023). Raising awareness of Inflammatory Bowel Disease. Available at: Raising awareness of Inflammatory Bowel Disease - gov.scot

[28] Diagnostic Waiting Times - Waiting Times at Scotland Level - Scottish Health and Social Care Open Data (nhs.scot)

Moreover, over 50% of patients were waiting longer than the government target of 6 weeks for a colonoscopy as of March 2025.[29] These delays reflect a year-on-year rising demand for diagnostic and therapeutic lower gastrointestinal endoscopies, inappropriate referrals, workforce vacancies and the prioritisation of cancer-related investigations.[30] **Alongside an emergency protocol to prioritise endoscopies by clinical need and outcomes until the backlog is resolved, implementation of the primary care diagnostic pathway for lower GI symptoms would allow GPs to better manage and triage patients, ensuring the right people are referred on to secondary care, thereby reducing pressure on endoscopy services and increasing early diagnosis.**

13.2. Research

To effectively advance treatment options and develop predictive and diagnostic algorithms to improve early diagnosis, NHS Scotland must consider how it can position patient organisations as anchor institutions and work in partnership with them to carry out research in these areas.

Opportunities for expanding treatment options for people living with IBD and other long-term conditions should be explored using data from UK Biobank and other health research databases.

Emerging data on genetic markers, protein markers, digital markers, and imaging must be used by NHS Scotland to develop predictive and diagnostic algorithms to improve early diagnosis and personalised approaches to treatment and care.

14. What barriers do people face making healthy decisions in preventing or slowing the progress of long term condition(s)?

14.1. Although the onset of symptoms of Crohn's and Colitis can have a profound impact on peoples' social, physical and psychological well-being, causing them to miss work, school, or avoid travelling and leaving the house entirely, many go for long periods without consulting a healthcare professional, often due to embarrassment, stigma, or a lack of awareness of the conditions.

14.2. As a result of our work, Scotland became the first nation to launch a new government-backed campaign to raise awareness of Crohn's and Colitis in 2023. The campaign raised awareness of the symptoms with posters and leaflets in community centres, GP surgeries, and social media, urging anyone who is concerned to contact their GP. Whilst the awareness campaign was a significant step and increased awareness of Crohn's and Colitis across Scotland, with awareness levels now above the UK average, a lot of people still haven't heard of the conditions or aren't aware of the symptoms. Crohn's and Colitis can present with symptoms such as diarrhoea

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[29] Diagnostic Waiting Times - Waiting Times at Scotland Level - Scottish Health and Social Care Open Data (nhs.scot)

[30] GIRFT 2021. Gastroenterology: GRFT Programme National Speciality Report. Available at: https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/10/Gastroenterology-Oct21v.pdf. Last accessed: May 2024.

and stomach pain, which may come and go every few weeks and months. Yet, 1 in 2 adults do not know these symptoms could be signs of Crohn's or Colitis.[31] This lack of awareness is contributing to significant patient led delays in early diagnosis. A recent IBD UK Patient Survey found that in Scotland, almost 4 in 5 adults experiencing symptoms of IBD waited over 4 weeks to see a healthcare professional and almost a third (29%) waited over a year.[32] This can be partly attributed to a lack of awareness of the conditions, common symptoms, and their seriousness.

14.3. **To address such delays in diagnosis which are increasingly contributing to worse patient outcomes and increased costs for the NHS, high-profile public health campaigns to raise awareness of the seriousness of IBD and its symptoms, such as the Crohn's & Colitis UK initiative 'Cut the Crap' and the Scottish IBD awareness campaign, alongside educational programmes in schools to educate children and young people on signs and symptoms of IBD, should be a priority for the Scottish Government to invest in, with support from dedicated experts and a focus on tackling inequalities in diagnosis.**

15. Is there anything currently working well within your community to prevent or slow progression of long term conditions?

16. How can the Scottish Government involve communities in preventing or slowing the progress of long term conditions?

16.1. It is essential to acknowledge that, as of now, there is no known way to prevent IBD. The Scottish Government must recognise this reality and refrain from suggesting that certain diseases can be avoided or imposing the burden of prevention solely on patients. Such implications are not only misleading but also undermine the complexities of living with these conditions. The Scottish Government does, however, have the opportunity to engage with communities in a proactive effort to enhance the management of these conditions, which can slow disease progression and improve overall health outcomes.

16.2. People living with long term conditions such as IBD should be equipped with comprehensive information on the various support services available to them in both medical and non-medical settings. A member of our community, who facilitates peer-support sessions, highlighted that fatigue is a prominent concern for people affected by IBD. Nevertheless, many people living with the conditions remain unaware of existing support services available to them. For instance, some local hospitals offer occupational therapy specifically designed for fatigue management and patients have the option to self-refer for this service. Unfortunately, there is a lack of awareness of this service, as some clinicians may be either uniformed about it or fail to communicate this information with patients.

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[31] Based on a survey of 10,000 people representative of the UK population commissioned by Crohn's & Colitis UK. Carried out by Censuswide and commissioned by Crohn's & Colitis UK in June 2022.

[32] IBD-Devolved-Nations-Report_Scotland_Final.pdf

16.3. We urge Health boards to conduct thorough research on support services available for individuals with chronic conditions in their local areas. It is vital that they compile clear, written resources that can be distributed in hospitals so patients are well informed about any services that may aid the management of their symptoms and support them to live well in the community.

16.4. We call on the government to allocate more resources to local hospitals and to extend support to charities and community voluntary groups (e.g. peer-support groups) providing support services. These organisations play a vital role in helping people manage symptoms, such as fatigue, associated with a number of long-term health conditions.