CROHN'S & COLITIS UK RESPONSE TO THE NHS 10–YEAR PLAN CONSULTATION

1. What does your organisation want to see included in the 10-Year Health Plan and why?

1.1. We are the patient charity representing people living with Crohn's and Colitis – two main forms of Inflammatory Bowel Disease (IBD).

1.2. Over 450,000 people live with Crohn's disease and ulcerative colitis in England – twice as high as the previous NHS estimates. This raises concerns about the health service capacity to meet the needs of these patients. The inadequate resourcing for health services means thousands of people may be left untreated and experience severe disease.

1.3. Inadequate service capacity planning is compounded by the broader challenges facing the NHS. These include high demand, long waiting times, strained budgets and a workforce under pressure. The 2023 IBD UK benchmarking[1] demonstrates that delays to diagnosis and treatment, combined with limitations to personalised care and a workforce in crisis, are placing additional strain on A&E departments and lead to avoidable hospital admissions. This comes at a cost, not only to the NHS, but also to the financial security, physical health, emotional wellbeing and quality of life of people with IBD.

1.4. Our key asks from the NHS 10 year plan are:

- Accountability for patient voice and outcomes
- Focus on prevention and early diagnosis
- Personalised, coordinated, and proactive care centred around wellbeing
- Improved administration and communication through data and care coordination

1.5. Accountability for patient voice and patient outcomes

1.5.1. The NHS 10 year plan should be underpinned by ongoing commitment to citizen engagement, patient insight, and coproduction. The plan must focus on building a culture of engagement based on the issues that matter to people, not just the issues which are important to the health service. A transformation of governance structures is needed to make the NHS more accountable to patients and communities.

1.5.2. We agree with Lord Darzi that "the NHS should aspire to deliver high quality care for all, all of the time." **It is important that the new performance regime that will result in 'league tables' will centre patient outcomes and clinical expertise, rather than enforcing top down targets**. We recognise that the NHS resources are finite, so when making decisions about who gets to access diagnostic tools, or who gets surgery first, the new plans should go beyond the simple

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[1] https://ibduk.org/

benign/malignant boundary and incentivise decision-making based on clinical outcomes, including disease progression or regression, functional status (e.g. activities of daily living), quality of life, patient satisfaction, adverse events (such as emergency surgery) and mortality rates.

1.6 Focus on prevention and early diagnosis

1.6.1 Quick access to diagnosis to reduce risk of deterioration

1.6.1.1 The NHS 10 year plan must address the long waiting times for referral, diagnosis and treatment. The latest service audit carried out by IBD UK shows that 75% report adults with suspected IBD waiting for more than the service standards, with 14% ending up being diagnosed following an A&E admission.[2] Delays to treatment narrows treatment options 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.

1.6.1.2 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.[3] **We ask that the government considers developing a framework to prioritise diagnostics such as endoscopies by clinical needs and outcomes until the backlog is resolved. This should include considerations for disease progression or regression, functional status (e.g. activities of daily living), quality of life, patient satisfaction, adverse events (such as emergency surgery) and mortality rates**.

1.6.1.3 **We recommend that the government views access to diagnostic services as a system wide problem that needs a system wide response.** This requires a move away from one access point only, as this will only shift unmet need around. For example, investment in endoscopies should be matched by increased capacity for histopathology to address waiting times for diagnosis of IBD.

1.6.1.4 **The lack of a clear patient-led diagnostic pathway in primary care for** lower gastrointestinal conditions mean people are not able to access the right tests at the right time.[4]

1.6.1.5 We ask that the government **publishes at regular intervals data about waiting times**, cancellations and referrals, and make this information usable for people to make decisions about their care. We know from people who contact our Helpline that patients are often not informed about what to expect in relation to the length

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[2] IBD UK, 2024, *The State of Care in the UK,* p 22.

[3] 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.

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

of waiting time. From a patient perspective, it is clear who is responsible for keeping them informed about how they long they will be waiting for their appointment. Accurate information and clear communication would help patients to plan and make decisions, such as work commitments, holidays, whether to pay privately (where this is possible) and caring responsibilities.

1.6.1.6 We also ask that the 10 year plan includes consideration for **people to stay well (self-management) as they wait.** We hear from patients every day about the psychological distress and feeling of hopelessness over time. 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 for IBD**. 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.**

1.6.1.7 The **government's plan should include partnership with charities that provide self-management support and services**. This 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.

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

1.7 Personalised, coordinated, proactive care centred around wellbeing

1.7.1 Care for IBD predominantly focuses on controlling gastrointestinal symptoms that leave people struggling with pain, fatigue, and mental ill health. These are the top reasons for lost working days. We know there are significant productivity efficiencies possible but this can only be achieved through personalised and coordinated care delivered by a multidisciplinary team (dieticians, psycho-social support, pain and fatigue management).

1.7.2 For those living with IBD, the lack of access to **personalised and multidisciplinary** support is consigning people to pain, and mental ill health for too long; this is limiting their chances to stay in work.

1.7.3 Improve access to specialist advice (consultant nurses) for primary care providers and patients to support management of long-term conditions.

1.7.3.1 More than 15 million people in the UK live with a long-term medical condition that cannot currently be cured. The number is set to rise by 23% over the next 25 years. Three out of every five people aged over 60 suffer from a long-term condition and about 85% of deaths are from long-term diseases. People with long-term health needs may require personalised support to help manage their health and their use of health and social care resources. It is essential that every person with a long-term condition has a care plan and has access to their health records, as well as care that is better coordinated around their needs. It is vital that GPs have access to consistent and good quality specialist advice about managing patients in the community and deciding on the potential hospital referrals.

1.7.3.2 E.g., specialist advice for people with IBD is often provided through IBD nurses. In the most recent IBD UK audit of services in 2023[5], which included responses from more than 17,000 people with IBD, the majority (87%) of adults felt that their IBD nurse was knowledgeable, yet only 37% felt that their GP was knowledgeable about their condition. IBD nurses can play a vital role in the education, coordination and support of ward teams and are central to the delivery of effective IBD care more broadly. However, currently the staffing levels for IBD nurses do not meet the safe standards, and do not have the capacity to meet the primary care demand.

1.7.3.3 **Recommendation: increase the number of consultant nurses, such as IBD nurses, so that patients can be supported to stay well in community and referred onto secondary care when appropriate.**

1.7.4 Improve communication between primary and secondary care

1.7.4.1 Currently GPs access specialist advice and guidance about potential hospital referrals through a myriad of formal and informal email addresses and telephone numbers, as well as the national e-referral system. Most channels tend to be standalone, do not provide any auditable data and, in most cases, they are disconnected from core patient administration or referral systems, which are run in the absence of agreed and consistent processes or response times. All of this can mean additional work and time wasted for GPs and hospital clinicians, as well as delays for patients in getting access to the most appropriate care.

1.7.4.2 E.g., whilst 99% of adult IBD services agreed that treatment changes in secondary care are communicated to primary care, with the majority stating that it takes <1 week for these changes to be communicated, 37% of adults with IBD did not think that their care was well organised between their GP and IBD team.

1.7.4.3 Ensuring greater integration between primary and secondary care when it comes to service delivery is essential. **Coordination could be enhanced by utilising electronic methods of communication (e.g. emails rather than letters) and technological innovation (e.g. linked databases).** Initiatives, such as the Personalised Care Toolkit[6], also provide guidance that can help to bridge the gap between primary and secondary care.

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[5] IBD UK, 2024, *The State of Care in the UK*

[6] https://ibduk.org/resources-for-ibd-services/personalised-care/about-personalised-care-toolkit

1.7.4.4 Finally**, patient communication systems should be coproduced with patients**, and should be tested with a variety of patients and staff to ensure people are not excluded from accessing care.

1.8 Improved administration and communication through data and care coordination.

1.8.1 To drive improvements in personalised care, NHS England needs to develop data structures to support personalised care planning and data sharing across multidisciplinary teams consisting of secondary care, primary care and allied health professionals.

1.8.2 NHS England should develop a programme of work to develop how continuity of care can be achieved through **multidisciplinary teams**, taking advantage of technology and the evolving role of care navigators so that we can meet the complexity of care of an aging population and growing number of people living with multiple long-term conditions. E.g. a virtual IBD ward has allowed the management of complex IBD patients safely and effectively as outpatients. The findings from this pilot in 2022 demonstrated a range of benefits including supported early discharge from hospital, low readmission rates and appropriate treatment escalation including colectomy.

2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Enablers*: access to specialist advice for primary care professionals, shared patient records and personalised care planning, supported self-management, rapid access to tests, alongside reforms to homecare medicine delivery services.*

Challenges*: the lack of shared data and interoperability of IT systems, and capacity both in secondary and primary care to deliver service transformation; and inadequate access to specialist advice (helplines) for patients and GPs to consult.*

2.1 Invest in specialist advice workforce to support primary and community health practitioners to better support people to stay well in community, to manage flares and avoid high-cost healthcare utilisation. For people with IBD, this will mean ensuring that there are enough **IBD nurses** to run advice and helplines locally.

2.1.1 People living with long-term conditions often face a significant health admin burden, managing both appointments and navigating a complex health landscape, especially when managing multiple conditions. **Patients could be better supported through a single point of contact for care co-ordination.**

2.1.2 Patients living with different long-term conditions may only make up a small proportion of patients that GPs will see. Enabling access to specialist advice for primary and community health systems is needed to help ensure **there is no wrong door approach for those seeking support** and enabling people stay well in the community, reducing high-cost healthcare utilisation.

2.1.3 E.g., GPs can lack confidence in managing IBD flare ups, especially with patients with comorbidities, in the community.[8] This often results in missed opportunities in managing flares, and patients being referred to their IBD team for issues that could be managed in primary care. This increases pressure on IBD teams and can contribute to delays to achieving remission allowing people to get on with their lives and a feeling of disjointed care for patients.

2.1.4 Access to specialist support for primary is challenged by the lack of adequate staffing for specialist roles, e.g. only 20% of IBD services meets the IBD Standards on staffing levels for nurses, even though they are the first point of contact for people living with IBD.

2.2 Personalised care

2.2.1 For people living with long-term conditions, especially those managing multiple conditions, personalised care plans offer improved opportunities to deliver continuity of care across multidisciplinary teams, GPs and allied health professionals and support better self-management of conditions and changes in health behaviour. Personalised care approaches have also been shown to reduce admissions and contact with the NHS.[2]

2.2.2 Approaches to the use of personalised care plans remain inconsistent and there are differences in understanding between patients and healthcare providers. E.g. 7% of adults with IBD that responded to the 2023 IBD UK Survey reported having a personalised care plan in place.[3]

2.2.3 Failure to coordinate between primary and secondary care limits the degree to which personalised care can be implemented. E.g. 37% of adults with IBD did not think that their care was well organised between their GP and IBD team.[4] This may lead to patients having to repeat their experience with each new care provider, wasting valuable clinic time and increasing the risk of information or opportunities for intervention being missed.

2.2.4 **NHS England must develop data structures to support personalised care planning and data sharing across multidisciplinary teams consisting of secondary care, primary care and allied health professionals.**

2.3 Patient Initiated Follow Up (PIFU)

2.3.1 People living with long-term conditions can also live with co-morbidities, meaning they may need to attend multiple appointments within the same or different teams, sometimes in different hospitals or trusts. Supported self-management – or patient initiated follow up (PIFU) - can help deliver care safely in the community. It also supports patients to be seen at the right time, freeing up routine clinic appointments for those with the greatest need such as those that are newly diagnosed awaiting treatment, reducing delays to care.[6]

2.3.2 **Decisions to initiate supported self-management should be made in partnership with patients based on their needs and clinical effectiveness**, as it may not be suitable for all due to the severity of their condition or low medical adherence.

2.3.3 Recognising the key role of specialist nursing in the delivery of self-management programmes, **NHS England should develop a national strategy for commissioning post-registration nursing education according to population need, and work with higher education institutions to deliver it sustainably.**

2.4 Direct access to tests

2.4.1 Tests for the monitoring of long-term conditions could be shifted to self-referral. E.g., new approaches adopted during the pandemic included regular faecal calprotectin home monitoring for those living with Crohn's and Colitis awaiting a colonoscopy to help inform triaging decisions, demonstrating the opportunity to shift aspects of care from hospitals into the community.[7] But without national leadership to drive strategic change, the benefits of these are not available to the majority of IBD patients.

2.4.2 NHS England should work with patient charities to drive innovation in direct access to screening programmes to support diagnosis and management of long-term conditions, such as IBD.

2.5 Homecare services

2.5.1 When homecare medicine services work well, they offer people the opportunity to continue their treatment in the comfort of their own home, reducing the costs of travelling back and forth to hospital and the impact on work or education.

2.5.2 However there are deep, systemic and long-standing failures in homecare medicine services. Nearly two thirds (62%) of people living with Crohn's and Colitis who responded to a recent charity survey told us that they have experienced problems with their homecare medicine service in the last six months. Common problems included a lack of communication and delays to delivery, leading to the need for additional hospital appointments to initiate treatment and potentially leading to a loss of response and flares.

2.5.3 The burden of these issues is also felt by clinical teams. Nearly half (49%) of the nurses responding to a charity survey told they spend at least half a day every week supporting patients having difficulties with their homecare medicine service with 12% spending a day or more.

2.5.4 The new KPIs to regulate the homecare services must focus on patient outcomes (e.g. clinical efficacy, adverse outcomes) and patient experience including communication.

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[7] [Point-of-care faecal calprotectin testing in patients with paediatric inflammatory bowel disease during the COVID-19 pandemic | BMJ Open Gastroenterology]

3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

3.1 Shared patient records

3.1.1 The lack of shared patient records for people living with long-term conditions managed in specialist services in secondary care with primary care reduces opportunities for prevention and early intervention, increase anxiety for patients and places unnecessary pressure on healthcare providers through increased admin and the need for multiple appointments.

3.1.2 This was most evident during the pandemic with the rollout of the shielding programme, and later vaccinations, for those on immunosuppressant medication, prescribed in secondary care. When shielding was introduced, patients receiving biologic treatments were not on any shielding list, or known to public health teams, due to these treatments being 'Hospital Only'. This highlights a disconnect between information shared between primary and secondary care

3.1.3 Data for prescriptions for a patient are accessible across primary and secondary providers through the delivery of a shared patient record.

3.2 Continuity of care across multidisciplinary teams

3.2.1 Personalised care plans offer the potential to tailor care to the needs of individuals, and deliver continuity of care across multidisciplinary teams, supporting people living with long-term conditions, especially those managing multiple conditions.

3.2.2 Coordination of care **could be enhanced by utilising electronic methods of communication (e.g. emails rather than letters) and technological innovation (e.g. linked databases).** Initiatives, such as the Personalised Care Toolkit, also provide guidance that can help to bridge the gap between primary and secondary care teams.[8]

3.3 Research

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

3.3.2 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.

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[8] What is the IBD Personalised Care Toolkit? | IBD UK

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

4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

4.1 Awareness

4.1.1 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. We ask that NHS England partners with patient charities to bring together the intelligence and builds a single symptom checker integrated with 111, A&E and app services to centralise the information for patients and healthcare professionals.

4.2 Lack of patient-centred diagnostic pathways

4.2.1 Whilst NICE provides guidance on the diagnosis of individual conditions, it does not provide pathways across conditions that present with overlapping symptoms.

4.2.2 E.g., a patient presenting with diarrhoea, stomach pain and fatigue could be experiencing one of a range of conditions from food poisoning, to IBD to bowel cancer. Yet, there is no nationally agreed pathway to help GPs decide which tests should be done and in which order. This results in (14%) adults waiting more than a year to be referred to a hospital after speaking with a healthcare professional about IBD symptoms and almost a third of adults (32%) did not receive a stool test for inflammation prior to hospital referral. We worked in partnership with patient charities and professional bodies to develop a new pathway to address these delays. Similar initiatives exist across the sector, e.g. Breathlessness pathway.

4.2.3 NHS England should collaborate with patient charities to drive innovation, from piloting to scaling up. This can include patient charities offering training and education to primary care professionals.

5. Policy Recommendations

5.1 Improve accountability through patient voice and focus on patient outcomes

Establish minimum standards for public consultation, engagement and coproduction for design, procurement and delivery of all health services. Monitor and publish performance against these standards.	Now
Improve administrative processes for patient to feedback about their experiences of the NHS.	Now
Move performance measures away from process and outputs and focus more on patient experiences and outcomes.	Medium-term
This should include improved experiences of health care supported by "I statements"; improved outcomes in terms of changes to people's health and wellbeing (e.g. their ability to manage their chronic illness, independence, quality of life, etc.) or proxy outcomes (such as reduced hospitalisation, and other avoidable utilisation of services) and better use of resources in a local area through joint approaches between the public, health and care systems, as well as the voluntary sector.	Medium-term
Review performance targets to ensure that targets are based on clinical needs and outcomes, e.g. targets around access to endoscopies or surgical prioritisation should be based on disease progression or regression, functional status (e.g. activities of daily living), quality of life, patient satisfaction, adverse events (such as emergency surgery) and mortality rates.	Medium-term

5.2 Prevention & Early Diagnosis

Partner with patient charities to integrate symptom checkers into NHS 111, NHS App and across the NHS more widely.	**Now**
Partner with patient charities to pilot patient-led diagnostic pathways, such as the lower GI pathway.	**Now**
Provide training and education to primary care professionals on how the pathway works so they are confident to use it appropriately and effectively.	**Medium-term**
Address barriers associated with variations or overly restrictive HR policies that may prevent NHS staff from working or training in NHS Trusts other than the one in which they are based to facilitate better regional collaboration and increase training opportunities such as for colonoscopy.	**Medium-term**
Partner with patient charities to pilot and scale up direct access to screening or diagnostic tests.	**Now**
Develop a framework to prioritise diagnostics (e.g. endoscopies) and surgeries by **clinical needs and outcomes** until the backlog is resolved. This should include considerations for disease progression or regression, functional status (e.g. activities of daily living), quality of life, patient satisfaction, adverse events (such as emergency surgery) and mortality rates.	**Now**

Publish data about waiting times, cancellations and referrals, in a way that can be used for people to make decisions about their care.	**Now**
Ensure capacity investments are made across the system, e.g. investment in endoscopies are matched with histopathology.	**Now**
Invest in supported self-management for people who wait for diagnosis and treatment, developed and delivered in partnership with patient charities.	**Medium-term**

5.3 Data and technology

Continue to press ahead with the public engagement to shape Data Saves Lives; and prioritise public recommendations on the linking of primary and secondary care data, including a focus on data within the GP health record.	Now
Standardise health IT processes to include hospital allied health input regarding patient function, social situation and recovery/management goals to facilitate a multidisciplinary collaboration, with greater consideration of individual needs and preferences especially during periods of transition.	Medium-term
Achieve a single shared care record which sits across all health and care settings and is interoperable with clinical workflow systems.	Medium-term
Achieve safe cross-organisation care delivery (including beyond Primary Care Network (PCN), Place, ICS or Regional boundaries) to ensure that patients are able to share their data across the boundaries.	Medium-term
Ensure greater integration of primary and secondary care by utilising electronic methods of communication (e.g. emails rather than letters) and technological innovation initiatives (e.g. linked databases).	Medium-term
Ensure there is accurate data of those prescribed immunosuppressant medication, and that all prescriptions for a patient are accessible across primary and secondary providers through the delivery of a shared patient record.	Medium-term

5.4 Shift from hospital to community

Increase the number of consultant nurses, such as IBD nurses, so that patients can be supported to stay well in community and referred on to secondary care when appropriate.	**Medium term**
Develop a national strategy for commissioning consultant nursing education according to population need, and work with higher education institutions to deliver it sustainably.	**Medium term**
Increase the number of specialist advice/Helplines available for primary care practitioners and patients for supported self-management of patients with long-term conditions, such as IBD.	**Medium term**

Develop a programme of work on continuity of care through **multidisciplinary teams,** technology and the evolving role of care navigators to meet the needs of people living with complex or multiple long-term conditions, e.g. virtual IBD wards.	**Now**