Launch of UK primary care diagnostic pathways for lower gastrointestinal symptoms in adults and children

Primary care diagnostic pathways for lower gastrointestinal symptoms

Title: Launch of UK primary care diagnostic pathways for lower gastrointestinal symptoms in adults and children

Short Title: Primary care diagnostic pathways for lower gastrointestinal symptoms

Authors: Shahida Din PhD[1,2], Astor Rodrigues MD[3], Pearl Avery[4,5], Neal Tucker MD[6,7], Debra Attwood on behalf of the Lower GI Symptoms Collaborative

Affiliations:

[1]Edinburgh Inflammatory Bowel Diseases Unit, Western General Hospital, Edinburgh, UK.

[2]Institute of Genetics & Cancer, University of Edinburgh, Edinburgh, UK.

[3]Oxford Children's Hospital, Oxford, UK.

[4]Wyke Regis and Lanehouse Medical Centre

[5]Dorset Healthcare University Foundation Trust

[6]General Practice, Oxfordshire

[7]NB Medical Education, Tyne & Ware, UK

Abbreviations:

GI	gastrointestinal
IBS	irritable bowel syndrome
NICE	National Institute of Care Excellence

Correspondence: Dr Shahida Din

Edinburgh Inflammatory Bowel Diseases Unit

Western General Hospital

Edinburgh

UK

Email: sdin@ed.ac.uk

ORCID ID: 0000-0003-2855-3400

Twitter: @ShahidaDin1

Key words: co-production

diagnostic delay

digestive diseases

gastrointestinal symptoms

Word count: 1181

Poor public awareness, stigma associated with gastrointestinal (GI) conditions, variability in knowledge and management of GI conditions, diagnostic waiting times, and multiple referral pathways and routes into UK specialist care are barriers to timely diagnosis and management of lower GI conditions. Therefore, a more integrated service is needed to ensure that the right patient is given the right diagnosis at the right time. The ideal situation would enable a prompt diagnosis tailored to patient's needs, reducing unnecessary travel, appointments, and investigations. Such an approach would support the healthcare service to achieve its broader sustainability goals with a system that is efficient and adaptable. In a bid to facilitate a timely correct diagnosis, people with 'lived experience' of a range of GI conditions, patient charities, and professional organisations co-designed a national unified lower GI symptom diagnostic pathway (Supplementary File), separate from the established cancer pathways. This was launched in July 2024 https://www.whatsupwithmygut.org.uk/. The co-production partnership is founded on the principle that consumers are best placed to design a service that meets their needs[1].

Lower GI symptoms, such as abdominal pain, bloating, altered bowel habit, faecal urgency, incontinence, and rectal bleeding occur frequently in the general population. These symptoms can also be associated with anorexia, weight loss, fatigue, poor sleep, anxiety, and depression, especially when they become chronic. There is reluctance to openly discuss how GI symptoms can affect nutritional, mental and sexual health. A cross-sectional population survey conducted in the UK from 2017[2] reported that patients were embarrassed about bowel symptoms, delaying presentation and for some diagnosis took a long time[3]. The fear, and shame of bowel symptoms may be compounded by inadequate public toilet provision[4,5] and poor societal awareness of hidden disabilities[6], discouraging individuals from leaving their homes.

Lower GI symptoms are associated with increased morbidity and mortality, and decreased quality of life. Getting the correct diagnosis as early as possible in a patient journey is vital for improving outcomes but delayed diagnosis is common. Delayed diagnosis can lead to reduced response to

medical treatments, a higher incidence of urgent and emergency care, and children may experience delayed growth hindering their physical and psychological development, affect their school attendance and prove detrimental to their education. The economic burden of digestive diseases is substantial, disproportionately affecting those in lower socioeconomic categories exacerbating existing healthcare inequalities. Reducing digestive diseases related premature mortality by 25% in 2019 would have resulted in estimated savings of approximately €1.77 billion in the UK[7].

Health literacy in the general population is variable and the limited availability of good quality patient focused resources do not meet the diverse needs of the modern population. Consequently, many patients will not seek formal medical help for their symptoms until severe. Patients and carers consume health information from a variety of resources such as social media platforms, patient charities, online symptom checker tools, pharmacists, and consulting with primary care physicians. When patients present with the classical symptoms of a specific condition, then the route to a diagnosis is straightforward. However, for most patients this is not their lived experience and the consulting health care professional (doctors, pharmacists, paramedics, advanced nurse practitioners, physician associates, practice nurses and health visitors) will be challenged with several disease specific triage pathways.

While a referral for suspected cancer or suspected inflammatory bowel disease may lead to direct access colonoscopy, other pathways may lead to clinic first approaches with Gastroenterology, Colorectal or General Medicine specialists. The different pathways may then lead to variations in time to diagnosis and treatment. Recognising that lower GI symptoms alone are poor predictors of specific conditions[8], the National Institute of Care Excellence[9] (NICE) and other national organisations[10–12] have produced disease specific guidance on the optimal investigation when a particular condition is highly suspected. While these strategies have undoubtedly improved the healthcare experience for some patients, the lack of data to support optimal implementation undermines the effectiveness of the current recommendations. Lower GI symptoms may also reflect non-GI conditions such as

endometriosis, and ovarian and bladder cancer, which can add to the diagnostic uncertainty. The increasing incidence of many lower gastrointestinal conditions in both children and adults and the fear of a missed diagnosis, results in a large number of referrals overwhelming a poorly resourced health care system.

The UK National Health Service has been under significant pressure in recent times which compounds the issues discussed already. This results in some patients experiencing waits of several years[13] for the correct diagnosis and treatment. Patient charities have ongoing concerns about the hidden impact of a delayed diagnosis highlighted by regular public awareness campaigns.

To address the challenges of a delayed diagnosis, pathways were co-produced by healthcare users, patient charities [Coeliac UK, Crohn's & Colitis UK, The IBS Network, The Crohn's in Childhood Research Association, and Guts UK], primary care organisations and specialist services and were supported by national professional organisations including The British Society of Gastroenterology, The Association of Coloproctology of Great Britain and Ireland and The British Society of Paediatric Gastroenterology, Hepatology and Nutrition. These organisations formed a steering committee, supporting the patient and clinician co-chairs who led the working group over a 12-month period. The working group included representation from all stakeholders and met bi-monthly to deliver the project. The finalised pathways have also been endorsed by the Royal College of Physicians of General Practitioners, The Royal College of Nurses, and the Royal Pharmaceutical Society.

The pathways are a tool to support decision making in primary care, balancing the clinical judgement necessary for a rapid diagnosis with the need to avoid testing everyone for everything (over investigation). Ultimately, the pathways support early diagnosis while also being an educational repository signposting to resources to help clinicians better support patients with their GI conditions during and after diagnosis. There is a strong emphasis on a comprehensive clinical history with typical and potential distinguishing symptoms for each of the common conditions. Live hyperlinks are embedded for disease specific pathways and a limited number of baseline blood and stool tests are

recommended to aid a timely diagnosis and facilitate enhanced triage when referred to specialist services. The safety netting of patients is equally important for those with chronic persistent symptoms that respond poorly to conventional treatments. The pathways are not for patients who are acutely unwell and nor for those in whom cancer is suspected who should be referred on the established pathways.

People with lived experience also co-developed and evaluated a complementary toolkit to help patients and carers to phrase relevant questions and communicate more clearly with healthcare professionals. The patient toolkit serves to improve patient understanding of their symptoms as well as managing expectations and facilitating shared decision making.

The primary care diagnostic pathways for lower GI symptoms are a critical first step in the patients journey to a timely correct diagnosis. This must be met with a commitment to provide universal access to non-invasive stool tests and improving compliance with the endoscopy waiting times for non-cancer conditions, only then will the delays to diagnosis be minimised across the healthcare sector, improving the quality of life for patient's living with lower GI symptoms.

ACKNOWLEDGEMENTS

Patients with lived experience who shared their healthcare journey and all members of the lower GI symptoms collaborative who developed the pathways.

AUTHORSHIP STATEMENT

Specific author contributions: Patient charities conceived the study. SD (Clinical Co-chair, Adult Consultant Gastroenterologist), AR (Paediatric Consultant Gastroenterologist), PA (GI Nurse Consultant) , NT (General Practitioner), DA (Patient Co-chair) drafted the manuscript. All lower GI symptoms collaborative authors reviewed and approved the final draft of the manuscript. The

corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Guarantor: SD is guarantor.

DISCLOSURES

SD grants from The Helmsley Charitable Trust, Edinburgh and Lothians Health Foundation, Pathological Society of Great Britain and Northern Ireland, Lord Leonard and Lady Estelle Wolfson Foundation, consulting fees from Abbvie, personal speaker fees from Janssen and Takeda, and meeting and travel grants from Janssen, Takeda, Lily, Abbvie and Dr Falk.

AR: payment for educational event from Galapagos Biotech.

PA: consulting fees from Sandoz Parma, Tillotts Pharma, and Abbvie, personal speaker fees from Tillotts Pharma, meeting and travel grants from Tillotts Pharma and BSG

NT: paid for producing and delivering CPD for NB Medical Education.

DA none

ETHICS COMMITTEE APPROVAL

Not required.

DATA SHARING STATEMENT

Not applicable.

References

1 Batalden M, Batalden P, Margolis P, *et al.* Coproduction of healthcare service. *BMJ Qual & Saf* 2016; **25**: 509 LP – 517.

2 Core Patient Charity. Findings from research with patients, caregivers, and stakeholders Alterline, London LSBU Technopark, 90 London Road, London, SE1 6LN. 2017.

3 Hawthorne AB, Glatter J, Blackwell J, *et al.* Inflammatory bowel disease patient-reported quality assessment should drive service improvement: a national survey of UK IBD units and patients. *Aliment Pharmacol Ther* 2022; **56**. DOI:10.1111/apt.17042.

4 Rickett O. Britain's desperate lack of public toilets says so much about our country. Guard. Newsp. 2020; published online June 27. https://www.theguardian.com/commentisfree/2020/jun/27/britain-public-toilets-coronavirus-private-interests.

5 Crohn's & Colitis UK. Access to toilets. ; : https://crohnsandcolitis.org.uk/media/ltodlerz/acc.

6 Newsroom. 'Grace's Sign' provides a lesson for us all. Scotsm. Newsp. 2019; published online April 16. https://www.scotsman.com/news/opinion/columnists/graces-sign-provides-a-lesson-for-us-all-leader-comment-1419727.

7 Rose TC, Pennington A, Kypridemos C, *et al.* Analysis of the burden and economic impact of digestive diseases and investigation of research gaps and priorities in the field of digestive health in the European Region—White Book 2: Executive summary. *United Eur Gastroenterol J* 2022; **10**. DOI:10.1002/ueg2.12298.

8 Ismail MS, Aoko O, Sihag S, *et al.* Lower gastrointestinal symptoms and symptoms-based triaging systems are poor predictors of clinical significant disease on colonoscopy. *BMJ Open Gastroenterol* 2020; **7**. DOI:10.1136/bmjgast-2018-000221.

9 NICE Guidance. Digestive tract conditions guidance. https://www.nice.org.uk/guidance/conditions-and-diseases/digestive-tract-conditions

(accessed Sept 30, 2024).

10 British Society of Gastroenterology. Clinical Resources: Guidelines. https://www.bsg.org.uk/clinical-resource (accessed Sept 30, 2024).

11 Association of Coloproctology of Great Britain & Ireland. Resources: Guidelines. https://www.acpgbi.org.uk/resources (accessed Sept 30, 2024).

12 British Society of Peadiatric Gastroenterology Hepatology & Nutrition. Gastroenterology Guidelines. https://bspghan.org.uk/gastroenterologyguidelines (accessed Sept 30, 2024).

13 Group A-IDDW. Sources of diagnostic delay for people with Crohn's disease and ulcerative colitis: Qualitative research study. *PLoS One* 2024; **19**: e0301672.