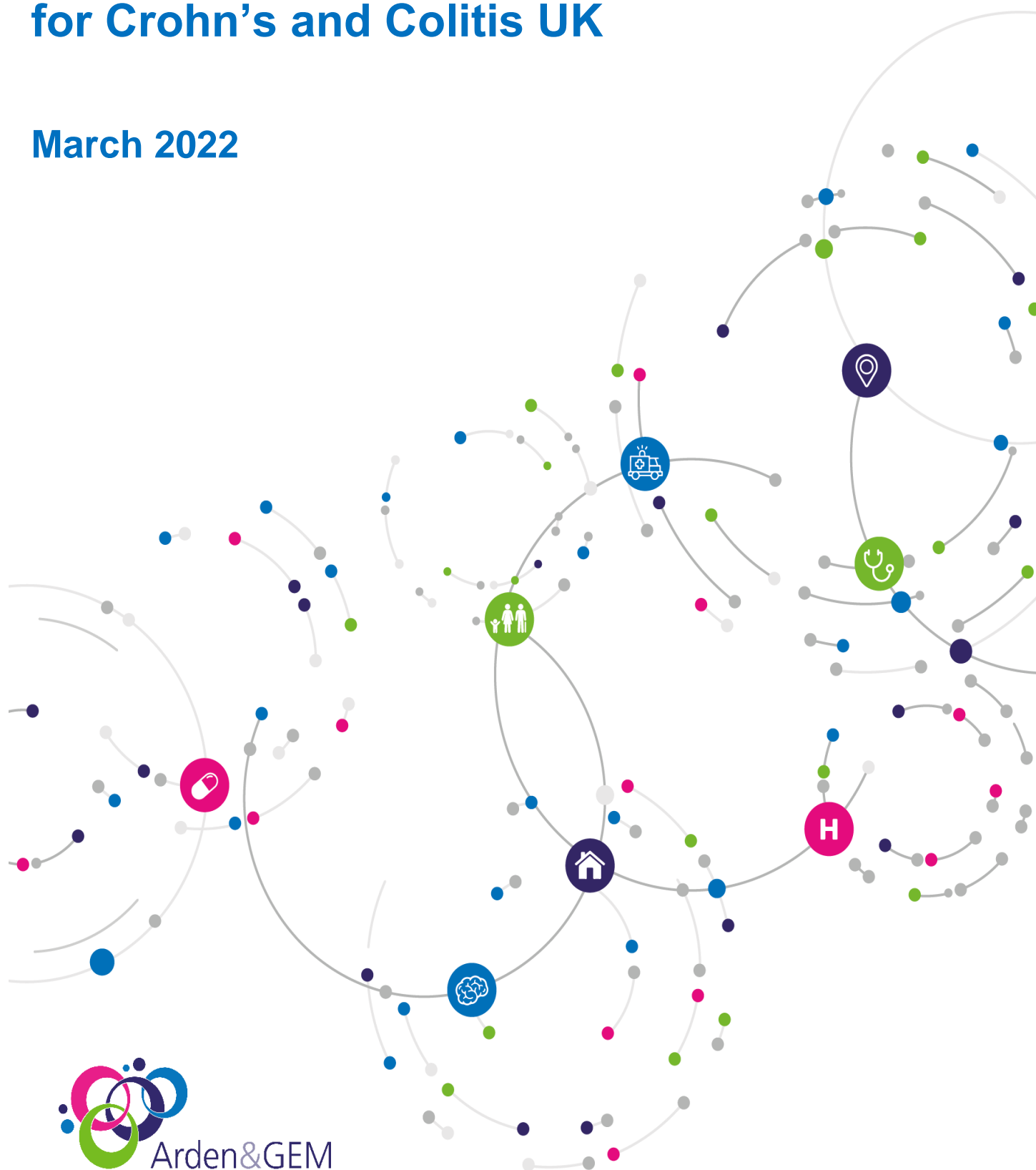


Understanding diagnostic delays in Crohn's and Colitis: an evidence review for Crohn's and Colitis UK

March 2022



1 Executive summary

1.1 Introduction

Crohn's Disease and Ulcerative Colitis are the most common inflammatory bowel disease (IBD) conditions (NICE 2013). The purpose of this evidence review is to help develop an understanding of where and why diagnostic delays occur in Crohn's and Colitis and to gain insights from how delays in diagnosis have been tackled in other comparative diseases which might help to address diagnostic delay issues in IBD. [NHS Solutions for Public Health](#) was commissioned by [Crohn's & Colitis UK](#) to produce this evidence review.

The key questions explored in this evidence review are:

1. What is the extent and nature of delayed diagnosis in people with Crohn's or Colitis in the UK and is there evidence for inequalities in the diagnosis pathway?
 - a. Frequency of delayed diagnosis and time to diagnosis by geographical area and population subgroups if available
 - b. Causes of delayed diagnosis/obstacles to early diagnosis at each stage in the diagnostic pathway, such as patient factors (demographics, awareness of symptoms and seeking medical help), primary care factors (GP awareness and referral process), system factors (such as access to laboratory investigations)
2. What has been shown to work in tackling delayed diagnosis of Crohn's or Colitis and other long-term conditions such as immune-mediated inflammatory conditions and conditions with primary symptoms expressed in the gut?

1.2 Methodology

This rapid evidence review was designed to identify, summarise and appraise the available evidence published since 1st January 2011. Searches for peer-reviewed studies were conducted on 20th December 2021 and 10th January 2022 on the electronic databases CINAHL, Cochrane Database of Systematic Reviews and Central Register of Controlled Trials, Embase, Health Management Information Consortium (HMIC) and Medline. Searches for grey literature reports included database searches on NHS Evidence conducted in December 2021 and a review of key websites conducted in January 2022. Further targeted Google searches to follow up particular details or initiatives were conducted in January and February 2022. Key stakeholders were also consulted for any relevant reports or studies.

1.3 Key findings

1.3.1 The key findings for question 1: The extent and nature of delayed diagnosis

Twenty-three studies assessing the extent and/or nature of delayed diagnosis in people with Crohn's or Colitis in the UK were found. The study designs included surveys, case series, cohort studies, case control studies, audits, analyses of primary and/or secondary care databases and qualitative studies. Most studies covered England or the UK and included both people with Crohn's Disease or Colitis with few reporting a breakdown of results by population subgroup or geographical area.

The studies highlight a wide variability of experience amongst people with Crohn's or Colitis with a substantial percentage of people waiting several months or even years for a diagnosis. However, due to the large heterogeneity between the study designs and results, they do not

provide a clear picture of how often diagnosis is delayed, by how much, and whether differences exist between Crohn's and Colitis, different population subgroups and geographical areas.

A wide range of different potential causes of delay were proposed within the studies relating to different aspects of the diagnostic pathway. These included:

- Lack of awareness or understanding of IBD, Crohn's Disease and Colitis for both the public and GPs which could affect both patient behaviour in seeking medical advice and GP behaviour in the management or referral of patients
- Patients' characteristics, including higher household income, previous diagnosis of irritable bowel syndrome and previous diagnosis of depression, all of which could also introduce potential delay by affecting patient and/or GP behaviour
- Factors relating to the provision of services including access to and confidence in using faecal calprotectin testing in primary and/or secondary care, access to endoscopy and staffing levels
- Factors relating to the organisation of services including variability in whether services had agreed referral pathways between primary and secondary care in place for people with suspected IBD, the speciality that patients are referred to and the frequency of multi-disciplinary team meetings.

Limited evidence was found on the causes of delayed diagnosis in population subgroups.

1.3.2 The key findings for question 2: Interventions aimed at tackling delayed diagnosis of Crohn's or Colitis and other comparative diseases

Three studies were found assessing the impact of interventions on time to diagnosis/treatment and duration of symptoms prior to diagnosis in patients with Crohn's or Colitis, all of which assessed faecal calprotectin testing in primary care. A further four studies were found on comparative diseases, all of which focussed on cancer diagnosis. The studies tended to be small with most having sample sizes of between 42 and 274 and were of low to moderate quality. The main quality issues were a lack of an appropriate counterfactual or comparator with no attempt to adjust for differences between the population characteristics of the groups and many of the studies being limited to one centre, often with poor reporting of baseline characteristics of study populations meaning that the representativeness of the study population could not be assessed.

The evidence around faecal calprotectin testing in primary care was inconclusive with none of the studies being able to reliably demonstrate a reduction in time to diagnosis. In terms of learning from comparative diseases, very few evaluated interventions were found. These were limited to a rapid diagnostic centre for patients with vague and/or non-specific symptoms suspicious of cancer, risk assessment tools for suspected bowel and lung cancer in general practice, a health awareness campaign for breast, bowel and lung cancer and two-week wait referrals for suspected upper and lower gastrointestinal cancers. Based on the volume and strength of the evidence found for each it was not possible to reliably determine the impact of the interventions on delayed diagnosis in these diseases and hence whether similar interventions may work for IBD.

Notably no relevant evidence was found for some interventions for which studies might have been expected. Such potentially relevant interventions include screening for IBD in high-risk

groups, training, educational materials and Regional Clinical Champions to improve understanding of Crohn's Disease and Colitis amongst healthcare professionals, or on improving the efficiency and productivity of service pathways and processes such as triaging, telephone straight-to-test pathways, increasing diagnostic testing and workforce capacity, different use of existing workforce such as community pharmacy and digitisation of services.

1.4 Conclusions and recommendations

The studies highlight a wide variability of experience amongst people with Crohn's or Colitis with a substantial percentage of people waiting several months or even years for a diagnosis. Few studies were found reporting findings for Wales, Scotland and Northern Ireland with most studies covering England only or the UK with no breakdown of results by country. Limited evidence was found to reliably determine whether inequalities exist across the diagnosis pathway.

It is recommended that a statistical analysis of the IBD UK survey data could be used to make comparisons by country, region and population subgroup (if recorded in the data) to more reliably determine whether any differences in delays in diagnosis exist by area and population subgroup within the UK (IBD UK 2021).

The evidence base surrounding interventions aimed at tackling delayed diagnosis of Crohn's or Colitis and other comparative diseases is limited. Only three studies were found assessing the impact of interventions on time to diagnosis and other related outcomes in patients with Crohn's or Colitis, all of which assessed faecal calprotectin testing in primary care and none of the studies were able to reliably demonstrate a reduction in time to diagnosis. A further four studies were found on comparative diseases, all of which focussed on cancer diagnosis. However, based on the volume and strength of the evidence found for each it was not possible to reliably determine the impact of the interventions on delayed diagnosis in these diseases and hence whether similar interventions may work for IBD. No studies were found on other similar immune-mediated inflammatory conditions.

There is a need for high quality studies with appropriate comparators and adequately powered sample sizes to reliably determine whether promising interventions improve time to diagnosis in IBD and ultimately improve health outcomes for patients. Given the paucity of evidence in the area, it is recommended that key stakeholders are consulted on their experiences of most promising interventions and pathway redesign to focus future research.