Crohn's & Colitis UK

Invitation to tender:

Investigating the impact of health inequalities on IBD outcomes, and exploring contributing factors through targeted research in selected communities in the UK

Contents

1. About Crohn's & Colitis UK

We are the leading charity for Crohn's and Colitis. Over 500,000 people are living with Inflammatory Bowel Disease (IBD) of which Crohn's and Colitis are the two main types. They are lifelong diseases that many people have never heard of. Due to the stigma and misunderstanding surrounding these diseases, thousands of people are suffering in silence.

We are working to improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We are here for everyone affected by Crohn's and Colitis.

For more information, please visit our website www.crohnsandcolitis.org.uk

We have existed as a charity for over 40 years and are moving into a new phase with a new strategy. A key element of the strategy is to develop a significant programme of work building evidence and insight into the lived experiences of people with Crohn's and Colitis. This tender is an important element of that programme.

2. Scope of Work

Background

Crohn's and Colitis are lifelong conditions that can significantly impact quality of life, yet health outcomes for individuals with these conditions can vary widely.

Health inequalities refer to avoidable and unjust differences in health outcomes observed across different population groups. These disparities can be seen in how long people live, the prevalence and severity of certain health conditions, and their access to appropriate care and support.

Health outcomes refer to changes in an individual's health status that result from healthcare or public health interventions. They are shaped by the broader social, economic, and environmental conditions in which people are born, grow, live, work, and age – often referred to as the **wider determinants of health**. Factors such as income, education, housing quality, and access to green spaces are interconnected and can significantly impact health and wellbeing. For example, individuals facing unemployment may also experience housing instability, limited access to nutritious food, and fewer opportunities for physical activity, all of which can exacerbate health conditions. Access to healthcare services is another critical factor influencing health outcomes. Barriers to accessing timely and appropriate care can be both structural and social, including service availability, transportation challenges, literacy and language barriers, gender-related discrimination, and previous negative experiences within the healthcare system.

These barriers are often more pronounced for **specific groups**, including those living in areas of high deprivation, Black, Asian, and minority ethnic communities, and inclusion health groups – such as people experiencing homelessness, those with drug and alcohol dependence, people in prison, vulnerable migrants, and others facing multiple layers of social disadvantage, including those whose identities may be less visible such as LGBTQIA+ and neurodiverse people.

To improve outcomes for people living with Crohn's disease and Colitis, a deeper understanding is needed of how health disparities are experienced and which communities are most adversely affected.

Project Objective:

This research aims to identify and analyse patterns of deprivation and health inequality across 20 pre-selected NHS hospitals, focusing on how socio-economic factors and specific vulnerabilities intersect to impact health outcomes for individuals with Crohn's and Colitis. The project should combine analysis of public datasets with targeted qualitative research to explore the underlying causes of these disparities, particularly among inclusion health groups, and to inform targeted interventions that reduce barriers and improve care.

A key component involves in-depth qualitative engagement with individuals with lived experience of IBD, to gain a detailed understanding of how these inequalities are experienced in practice. This includes mapping the patient journey across the IBD care pathway, identifying critical barriers, and highlighting points where access, experience, or outcomes are adversely affected. Together, insights from both data analysis and lived experience will support practical recommendations for service improvement, policy development, and more inclusive care delivery.

Project Structure and Bidding

This research initiative is structured into two distinct but complementary projects.

Bidders are invited to submit proposals for either one or both projects according to their expertise and interest:

- **Project 1** focuses on quantitative analysis to identify and analyse patterns of deprivation and health inequality across the selected 20 NHS hospitals. It includes examining socio-economic factors and vulnerabilities to develop a prioritisation framework and shortlist key areas for more detailed study.

- **Project 2** involves an in-depth qualitative exploration of patient experiences within the areas identified in Project 1. This phase places strong emphasis on authentic engagement with people with lived experience of IBD, aiming to map patient journeys, identify barriers, and generate actionable recommendations for service improvement, policy, and community support.

Bidders should demonstrate relevant expertise aligned with the scope of the project(s) they intend to undertake, along with a proven track record in addressing health inequalities.

Defining Poor Health Outcomes

As part of an earlier stage of work, Crohn's & Colitis UK has analysed data from selected questions from the IBD UK 2023 Patient Survey, which gathered responses from over 17,000 individuals living with IBD. This analysis was used to develop a set of proxy indicators highlighting potential barriers to care. Based on this, 20 NHS hospitals across the UK have been prioritised for more detailed analysis in this project. While these indicators do not confirm poor outcomes outright, they offer a practical framework to prioritise a number of NHS Hospitals for further analysis. The indicators reflect a combination of clinical, treatment-related, and personal experience factors, including:

- **Timeliness of care** - time from initial GP consultation to referral, and from referral to diagnosis
- **Diagnostic process** - how the diagnosis was made
- **Treatment burden and intensity** - number and duration of steroid courses taken within the past 12 months
- **Healthcare utilisation** - reflected in recent hospital admissions and surgeries within the past two years
- **Patient experience** - perceived quality of care and experiences of stigma or unfair treatment related to IBD in the past 12 months

Project 1:

Suggested Approach:

We welcome creativity in addressing this Project and encourage innovative solutions, but for the purpose of guiding this process, a suggested 3 Phase approach could be as follows:

Phase 1: Analysis of deprivation levels across the selected 20 NHS hospitals

Aim: Assess deprivation levels across the 20 selected NHS hospitals using viable datasets that capture socio-economic and environmental factors.

Deliverables:
- A deprivation profile for each NHS hospital*
- A scorecard and ranked list of NHS Hospitals based on levels of socio-economic disadvantage

This phase is intended to be straightforward and foundational. We do not require in-depth comparative analysis between different areas. The primary objective is to prioritise and rank the areas based on a consistent set of indicators.

Phase 2: Analysis of vulnerable population groups across the same 20 NHS hospital areas

Aim: Understand the demographic and social composition of the populations in each of the 20 NHS hospitals, with a focus on identifying areas where specific population groups who may be at heightened risk of exclusion or poorer health outcomes are more concentrated. This analysis should go beyond overall deprivation to explore the distinct demographic, and social characteristics present across each service areas. This may include (but is not limited to) ethnic minority communities, people experiencing homelessness, those with drug and alcohol dependence, people in prison, vulnerable migrants, and others facing multiple and intersecting forms of disadvantage, including those whose identities may be less visible such as LGBTQIA+ and neurodiverse people.

Deliverables:
- A demographic and vulnerability profile for each NHS hospital area*
- Identification of areas with comparatively higher concentrations of socially excluded or vulnerable groups, and potential barriers to accessing care

**The 20 NHS hospitals are identified based on aggregated patient survey data and may not align perfectly with standard geographical boundaries and datasets (e.g. IMD, ONS). The research team is expected to make the best possible match using available data, such as using local authority boundaries as proxies for hospital catchment areas.*

Suggested data sources for Phases 1 and 2:

While the selection and application of datasets are to be determined by the research team, the following are key datasets that should be considered for the analysis:

- **Index of Multiple Deprivation (IMD)** – For general deprivation indicators (e.g. income, employment, health, housing). Note: The current IMD dataset is based on 2019 indicators; researchers should anticipate the forthcoming 2025 update and consider its potential implications for the analysis.
- **Consumer Data Research Centre (CDRC)** – For socio-economic and environmental data.
- **Office for National Statistics (ONS)** – For demographic data, including ethnicity and housing.
- **Core20PLUS5 framework** – To guide the identification of high-need populations and ensure alignment with NHS health inequality priorities.

The research team is encouraged to incorporate other relevant data sources beyond standard national datasets to provide deeper insight, particularly into the experiences of inclusion health groups. These may include local authority health reports, inclusion health datasets, academic literature, and data from specialist charities or community organisations. Bidders should specify how they will triangulate the data to create a more nuanced and inclusive understanding of vulnerability, including groups often underrepresented or "data-invisible" in conventional datasets, such as LGBTQIA+ and neurodiverse populations.

Phase 3: Cross-referencing data to identify overlapping vulnerabilities

Aim: To identify areas where general deprivation (Phase 1) and concentrations of vulnerable groups (Phase 2) overlap, highlighting 'high-risk' locations where compounded inequalities may lead to poorer health outcomes.

A subset of 5 locations will be selected for targeted qualitative research. The selection criteria should consider, where possible:

- High levels of deprivation and vulnerable group concentration
- Geographical and demographic diversity (urban/rural; across UK nations)
- Practical viability for participant recruitment, prioritising areas with available and willing participants to ensure a robust qualitative sample

Deliverables:

- A prioritisation framework to support the selection of areas for in-depth qualitative research
- A shortlist of 5 locations demonstrating the greatest overlap of poor health outcomes, deprivation and vulnerability

Project 2

In-depth qualitative exploration of patient experiences in selected areas

The findings from Project 1 should inform the design and focus of Project 2.

Aim: This phase will explore the experiences of people diagnosed with IBD in the five identified areas who have faced additional barriers due to health inequalities. The goal is to better understand how these inequalities arise and impact patients throughout the IBD care pathway - from initial symptoms through diagnosis, treatment, and ongoing care - and to identify opportunities for both service improvements and enhanced patient support to better meet the needs of all communities.

As a first step, Project 2 could include engagement with community members and/or experts who have broader knowledge of health inequalities (e.g. through interviews). This engagement will help shape the research approach and ensure it reflects wider contextual understanding of barriers and disparities.

All lived experience participants should have a confirmed IBD diagnosis. The research will focus on individuals who have encountered additional barriers related to social, cultural, economic, or systemic inequalities in their care journey.

Bidders should describe how their recruitment strategy will apply an intersectional lens by actively seeking participants who reflect multiple, overlapping dimensions of diversity and lived experience (e.g. race, gender, disability, sexuality, class) where possible, to ensure the research captures the complex and compounding nature of inequality.

Key research questions may include:

- Did you ever delay seeking care? If so, what were the reasons?
- What barriers did you face getting diagnosed or treated for IBD?
- Were there times when you felt the healthcare system didn't work for you? Why?
- Did you feel your background (e.g. ethnicity, culture, language) affected how you were treated or understood?
- In what ways did your financial situation, housing, employment, or immigration status affect your care?
- What do you wish you'd known earlier in your e?
- What advice would you give someone going through a similar experience?
- What changes would you like to see in IBD services for people in similar situations to yours?

Deliverables:

- Retrospective journey maps illustrating patient experiences across the IBD care pathway. This could inform persona-based profiles representing typical patients with diverse lived experiences.
- Identification of barriers and key points where inequalities arise
- Recommendations for:
  - Service and pathway improvement
  - Policy and commissioning
  - Charity-led support, education, and advocacy

Research Methods could include:

- Surveys and focus group discussions with individuals who meet the inclusion criteria, to explore experiences of healthcare access, diagnostic delay, treatment availability, and overall outcomes.
- Engagement with healthcare professionals and community stakeholders to explore barriers to effective IBD care, particularly for marginalised groups.

Success Criteria:

1. **Identification of barriers to accessing IBD care and support:**
   Provide clear, actionable insights into both structural and personal barriers through combined quantitative and qualitative research.

2. **Meaningful Patient and Public Involvement (PPI):**
   Demonstrate a clear plan for active involvement of people with IBD, including participation in governance, input into research design, and opportunities to review and sense-check analysis and findings. This approach should ensure that lived experience perspectives actively shape the research process and outputs.

3. **Targeted interventions and policy recommendations:**
   Deliver practical recommendations for interventions, policies, and service improvements that will inform Crohn's & Colitis UK's advocacy efforts to reduce health disparities in IBD care.

4. **Post-project deliverables:**
   Produce a comprehensive report with an executive summary and presentation summarising findings from the completed project(s). The report must be submitted in a format prescribed by, and approved by, the Charity before publication. The Charity will review the report, may provide feedback or request edits, and the publication date and plan must be agreed with the Charity.

5. **Effective handover and collaboration for potential subsequent phases:**
   Ensure all data, findings, methodologies, and key contacts are clearly documented and communicated to facilitate a smooth transition to any likely follow-up co-production work or third-phase project, supporting continuity and collaboration with future teams or partners. Where appropriate and ethically feasible, bidders should consider how relationships - whether with participants, community organisations, or other stakeholders - can be sustained or referred onward (e.g. via participant opt-in or collaboration with trusted intermediaries) to enable meaningful continuity of engagement.

These outputs will inform Crohn's & Colitis UK's advocacy efforts and raise awareness among healthcare providers, policymakers, and other stakeholders about systemic barriers and health inequalities affecting marginalised groups, drawing on both the quantitative analysis of deprivation patterns and the qualitative insights from people with lived experience.

Why this project matters for Crohn's & Colitis UK

- Uncover hidden barriers **and i**dentify the real-life obstacles people with IBD face - including personal challenges that could include fear, stigma, limited understanding or awareness, and difficulty advocating for themselves, as well as systemic issues like long waiting times, inconsistent care quality, or discrimination.

- This project will move beyond general discussions of inequality by targeting communities with the most severe disparities. By identifying these areas and gaining insight into their unique challenges, the research will develop practical, locally tailored solutions that can be scaled and adapted to improve access, quality, and outcomes across the UK.

- Engage people and communities often excluded from research and decision-making, ensuring that future services better reflect diverse needs and lived experiences.

- Position the Charity as a leader in inclusive care by actively addressing health inequalities - not only treating symptoms, but helping to create a fairer, more responsive IBD care system for all.

Previous Research Commissioned by Crohn's & Colitis UK

Crohn's & Colitis UK have commissioned several studies to examine healthcare disparities in IBD. These findings provide important background information for this project:

Social and Economic Factors Affecting IBD Care and Outcomes:
A scoping review, commissioned by Crohn's and Colitis UK, was conducted to systematically map the evidence base on the social and economic factors influencing outcomes in IBD. The review focused on identifying the most significant determinants, including ethnicity, socio-economic status, gender, and access to treatment, in shaping disease severity and care experiences for IBD patients. The review, which analysed 77 studies covering over 1.2 million participants, identified important gaps in research and suggested areas for further investigation.
Key findings from the review highlighted that race plays a significant role in both disease incidence and management. For example, South Asian patients in the UK were found to have a higher incidence of more severe Crohn's and Colitis but lower rates of biologic therapies. Socio-economic factors, including lower-income status, were associated with less participation in peer mentoring or educational programmes, although unemployed individuals reported better health outcomes. There was also a need for further exploration of gender and cultural barriers, especially in relation to young and ethnically diverse populations.
While the review provided valuable insights, it also pointed out substantial gaps in the research, particularly around the causes of these disparities and the need for more nuanced research methods to explore these complex issues.
This scoping review serves as an important background resource for understanding the current landscape of healthcare disparities in IBD.

Other notable projects:

- **Socioeconomic Disparities:** The increasing trend in reported IBD prevalence from the most deprived to the least deprived suggests that inequities in healthcare access and detection may be influencing diagnosis rates. The least deprived populations may experience higher diagnosis rates due to better access to healthcare and screening, while the most deprived groups may have lower reported prevalence due to underdiagnosis, delayed diagnosis, or limited access to medical services, rather than a true lower incidence of the disease. (Nottingham, 2021)

- **Engaging Black Communities:** Black communities are diverse, and research must align with participants' interests. Culturally aware, inclusive approaches are essential for fostering participation. Honest, collaborative storytelling that avoids tokenism is crucial for meaningful engagement. (Clearview, 2023)

- **Communication Preferences:** Younger people and ethnic minorities prefer direct language when discussing health, whereas older individuals tend to favour more subtle or coded terms. While 76% of participants felt comfortable discussing symptoms with a doctor, only 16% were comfortable discussing them with an employer. (Kohlrabi, 2023)

- **Financial and Social Concerns:** Of 12 prioritised factors, financial concerns ranked highest, followed by social issues such as stigma and isolation. This underscores the importance of addressing both economic and social barriers to care. (Egality, 2023)

- **Diagnostic Delays:** Limited evidence was found regarding inequalities in diagnostic delays, preventing any definitive conclusions on this issue (NHS Arden and Greater East Midlands, 2022)

Copies of these reports are available upon request

In addition to the studies commissioned by Crohn's & Colitis UK, there are numerous other studies exploring healthcare disparities in IBD.

For example:

'*Inequalities in Healthcare Access, Experience, and Outcomes in Adults with Inflammatory Bowel Disease'*
51 studies were included. Of these, 34 were from the US, 7 from the UK, and the rest from other countries. The studies were categorised into three primary themes: health outcomes (42 studies), healthcare access (24 studies), and patient experience (8 studies).The review found significant healthcare inequalities in IBD care, particularly for Black, Asian, and Hispanic populations, who experienced worse health outcomes, including higher rates of complications, hospital admissions, and limited access to biological and surgical treatments. Socioeconomic status, rurality, and distance from healthcare also contributed to disparities. While much of the research has focused on unequal health outcomes, there is a notable gap in understanding patient experiences and access to care, especially in underserved groups such as LGBTQIA+ individuals and those with learning disabilities or autism. The review emphasises the need for further research and service changes to address these healthcare inequalities in IBD care {https://academic.oup.com/ibdjournal/article/30/12/2486/7643907

This project is part of our Evidence and Insight programme, dedicated to identifying and addressing gaps in the current knowledge of Crohn's and Colitis. Our aim is to understand the experiences of all those affected by Crohn's and Colitis, including those from underserved groups. For more information about our Evidence and Insight programme click here.

Detailed specifications

We expect the project to take up to 6 months but are open to considering applications that would require slightly longer timeframes, if the justification for this is clearly shown.

We welcome bids of up to £85,000 for the whole project. Higher value bids may be considered if adequate justification can be given for the additional amount. If the project were to be split into two separate contracts, we estimate the cost split would be approximately 10:90 between Project 1 and Project 2.

Please note that the costs and timeframe outlined for this project serve as a guide, and we welcome discussions to explore and assess the feasibility of these requirements.

3. Tender submission

Your tender submission should include the following:

Proposal for services

We would like you to set out the following:

- a summary project plan highlighting the methodology and key dates to demonstrate how you would meet the brief by the proposed deadline
- how you will address issues of equality, diversity and inclusion (EDI) in your work
- details of key personnel who will be involved in the project
- key risks and mitigating actions for the project
- an explanation of the unique benefit your organisation will bring to this work
- an indication of how much input and capacity would be required from the charity team
- detail of any elements of the work that would be provided by another company/freelance staff
- details of how you propose to ensure GDPR compliance, as appropriate
- your fee proposal should give a detailed breakdown of costs, itemised for each separate element of the tender and exclusive of VAT.

In addition, we would like you to:

- briefly outline your values, structure, size and capabilities in general
- provide examples of similar projects or reports you have delivered
- provide examples of previous work in PDF or Word format
- list two previous clients (preferably not for profit) that we can contact for reference purposes
- provide your organisation name, address, registered address (if different) and website address
- provide primary person’s contact details
- provide a copy of your Equality, Diversity & Inclusion (EDI) policy.

4. Selection Criteria

Responses will be evaluated by the charity using the following criteria (in no particular order):

- Ability to deliver on all required services or outputs
- Access to appropriate sources of evidence
- Ability to deliver within specified timescales
- The quality and clarity of the proposal
- Evidence of proven success in similar projects
- Responsiveness and flexibility
- Transparency and accountability
- Value for money
- Financial stability

5. Key dates

Date	Task
Thursday 21st August, 2025	Invitation to tender launched
9am Monday 22nd September, 2025	Submission of tender
Week beginning Monday 6th October, 2025	Interviews of shortlisted bidders
Week beginning Monday 13th October, 2025	Award of tender
Week beginning Monday 20th October, 2025	Project work commences

6. Instructions for return of tender

Crohn's & Colitis UK Contact Person

Please send an electronic version of your proposal, plus any appendices, to Sarah Kelemen at sarah.kelemen@crohnsandcolitis.org.uk by 22nd September **at 9:00am**

Confidentiality

The contents of this document and any accompanying documents contained herein is the property of Crohn's & Colitis UK unless otherwise stated and may not be disclosed in part or in full to any third party without the prior consent of Crohn's & Colitis UK. This also extends to all documents that might be supplied in connection with the project or its implementation now or in the future.

All information obtained by Crohn's & Colitis UK from the bidders in connection with this tender will be treated in confidence. Any documents supplied by Crohn's & Colitis UK remain the property of Crohn's & Colitis UK, and their return may be requested.

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Bid conditions

We reserve the right to disqualify any bidder from the selection process at any stage. In particular, the following events may lead to disqualification:

- any proposal received after the specified deadline
- any proposal that fails to conform in procedure, format, sequence substance of the requirements presented in this document
- failure to substantiate claims made in the response to this tender
- any breach of confidentiality.

Costs of response

Crohn's & Colitis UK will not be responsible for any costs incurred by bidders prior to signature of any formal Agreement, including those incurred in responding to this invitation and negotiating any Agreement. All activities which bidders carry out to properly demonstrate the viability of their proposals including demonstrations and presentations will be at their own cost. In turn, we will be responsible for our own expenses and costs throughout the tender and negotiating period.

Right of non-selection

Although it is currently intended that the procurement will take place in accordance with the provisions of this document, we reserve the right to terminate, amend or vary the procurement procedure by notice in writing at any point up to the signing of the Agreement. In the event of such termination, amendment or variation or otherwise, we shall not have any liability for any costs, expenses or other resources incurred by yourselves in participating in this procurement as a result of such termination, amendment or variation.

We do not bind ourselves to accept the lowest or any tender. The procedures described in this document are for guidance only.