

Invitation to Tender: To conduct a modelling study to determine the economic costs of Crohn's and Colitis in the UK.

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. Because of 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 web site 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 early element of that programme.

2. Scope of Work

We wish to undertake an economic modelling study to understand the economic cost of a diagnosis of IBD on individuals and families affected by Crohn's Disease, Ulcerative Colitis, Microscopic Colitis and Unclassified IBD. We are especially interested in understanding how these costs differ when there is a delay in diagnosis.

We would like to understand:

- The lifetime financial impact of living with Crohn's or Colitis both to the individual and the NHS
- The economic impact associated with delayed diagnosis both to the individual and the NHS
- What is the economic cost to society that arises due to an IBD diagnosis, e.g. from impact on work and education?
- Does economic impact vary based on demographic variables such as gender, ethnicity and location within the UK?

Background

A recent study jointly funded by Crohn's & Colitis UK and Coeliac UK has found that over 500,000 people in the UK have IBD, meaning 1 in every 123 people. IBD can be extremely debilitating and impact on every area of a person's life, including work, travel and relationships. Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and associated anxiety and depression.

Living with IBD comes at a cost to the individual and to society. Lifetime costs for IBD are comparable to a number of major diseases, including heart disease and cancer (Luces and Bodger, 2006). The annual cost of treating a flare (relapse) of Ulcerative Colitis or Crohn's Disease is up to six times greater than treating a patient in remission (Ghosh and

CROHN'S & COLITIS UK

Premchard, 2015). 33% of people with a long-term health condition do not pick up prescriptions due to cost (Prescription Charges Coalition, 2017). 57% of people living with Crohn's and Colitis have had to reduce their working hours due to their ill-health (Gay et al, 2011). They may pay an additional £80-£250 per travel insurance policy. A Danish register-based study also demonstrated individuals with IBD had significantly higher health costs in each of the 10 years before diagnosis relative to controls (Blackwell et al., 2021).

Recent research demonstrates that many struggle to get a timely diagnosis despite reporting symptoms to their GP. A recent systematic review of 30 studies, commissioned by Crohn's & Colitis UK (available on request), highlighted 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. The proportion of people waiting for a diagnosis varies across the UK. For example, the proportion of adults who waited more than six months for a diagnosis ranged from 38% in England to 48% in Wales. For children this ranged from 26% in Scotland and Northern Ireland to 44% in Wales. However, the number of patients with data available from the four UK countries varied considerably, with more than 70% of the data collected coming from England and the countries were not statistically compared.

As the number of people living with IBD is rising, it is vital that we understand the financial challenges they face, and the total cost of delayed diagnosis to the individual, NHS and wider UK economy, in order to campaign for change. The need to understand the economic challenges of IBD has also been heightened by the wider-scale financial challenges facing the UK population at present due to rising inflation. While the cost of living is increasing for all, it is imperative that we understand the additional economic burden of Crohn's and Colitis.

Project Outline

In this project, we are looking to develop an understanding of the economic impact of Crohn's and Colitis on the: cost to the NHS, cost to an individual (over a lifetime) and lost opportunity cost. We are particularly interested in learning about the impact delayed diagnosis has on these areas.

Whilst we will look to the bidders to describe the appropriate methodology to gain valid and robust insight that explores the above areas; fundamentally, this project should use a robust methodology that is sufficiently representative of the UK IBD population and cover, as a minimum:

- The lifetime financial impact of living with Crohn's or Colitis both to the individual and the NHS
- The economic impact associated with delayed diagnosis both to the individual and the NHS
- The economic cost to society that arises due to an IBD diagnosis, e.g. from impact on work and education
- Whether the economic impact varies based on demographic variables such as gender, ethnicity and location within the UK

We anticipate this be a significant project for our organisation and we are eager to hear your perspective on what the best methodological approach is to get the insight we need.



Detailed specifications

We expect the project to take **12 months**, but are open to considering applications that would require slightly longer timeframes, if the justification for this is clearly shown.

The final report should take the form of a Word document which the charity will either publish in its entirety, or in component parts or in summary form.

We would consider the potential for academic publication, but we wish to use the results to inform our work in 2022/3 and academic publication must not delay this.

We welcome bids of up to £100,000 for the whole project. Higher value bids may be considered if adequate justification can be given for the additional amount.

We also welcome bids that only cover part of the project scope.

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
- 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
- Demonstrate your understanding of working with diverse populations
- Provide examples of similar projects or reports you have delivered
- 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 the primary person's contact details
- Provide a copy of your Equality, Diversity & Inclusion (EDI) policy

4. Selection Criteria

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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
7 th of July	Invitation to tender launched
9 a.m. on 19 th of September	Submission of tender
Week beginning 3 rd of October	Interviews of shortlisted bidders
Week beginning 10 th of October	Award of tender
Week beginning 17 th of October	Project work commences

6. Instructions for return of tender

Crohn's & Colitis UK Contact Person: The successful bidder will report directly to Rachel Ainley (<u>Rachel.Ainley@crohnsandcolitis.org.uk</u>)

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.