

Crohn's & Colitis UK

**Invitation to tender to scope metrics and indicators for tracking
quality of life for people living with Crohn's and Colitis
in the UK**

February 2024

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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 & Colitis UK aims to gain a deeper understanding of aspects of life that are significantly impacted by the experience of living with Crohn's and Colitis. Projects are ongoing to identify the top 10 impacts on quality of life from living with Crohn's and Colitis, across health and non-health factors. The charity aims to establish a measure of quality of life by identifying the social, economic, and health factors influenced by these conditions, and assessing the diverse degrees of impact each factor has on the community.

This research will feed into a public facing **Quality of Life Dashboard** that we are in the process of developing, designed to provide a visual representation of the health and non-health impacts that matter most to our community. Collaborating closely with patients, stakeholders, and external agencies, we are engaged in a co-production approach to ensure that the dashboard authentically represents the highest priorities of those living with Crohn's and Colitis in the UK.

The first iteration of the Dashboard is set to launch in December 2024.

Guided by the priorities expressed by those living with these conditions, the Quality of Life dashboard will employ carefully selected metrics to illustrate the trajectory of improvements or deteriorations in quality of life over time.

The Dashboard has various purposes and will serve a diverse audience. It will:

- Guide policymakers on improving community well-being, informing lobbying and campaigning efforts
- Underpin the strategic priorities for Crohn's & Colitis UK
- Reassure individuals with Crohn's and Colitis, advocating for the issues most affecting them
- Inform the public and promote awareness of the conditions
- Assist academics in identifying research priorities
- Provide healthcare professionals with patient-centric insights
- Equip media with up-to-date data for highlighting areas needing change

This initiative will stand as a testament to our commitment to understanding, representing, and improving the lives of our community.

Project Outline

We are seeking research partners who are experienced in methodologies for scoping and developing quality of life metrics and indicators, to effectively capture and accurately represent the lived experience of people with Crohn's and Colitis.

We have commissioned research to identify the top 10 priorities of people living with Crohn's and Colitis to identify the impacts on quality of life. Results are expected end-Q2 2024. Preliminary insights suggest that financial security and health will be prominent, prompting us to first focus on developing indicators in these areas.

Key requirements:

1. Conducting a Comprehensive Review

- Conduct a thorough review of all publicly available data relating to the all health and non-health aspects of living with IBD to establish what datasets, indicators, and metrics exist.
- Ensure that the review focuses on all data specific IBD and avoids duplicating known information already familiar to the charity from previous work. For example:
 - The IBD UK Benchmarking surveys (see additional information below)
 - The epidemiology report on IBD conducted by the University of Nottingham titled 'Contemporary epidemiology of coeliac disease, dermatitis herpetiformis, Crohn's disease and ulcerative colitis in the UK' (see additional information below)
 - The scoping review conducted by the University of Central Lancaster titled 'The impact of social and economic factors on outcomes within people living with Crohn's and Colitis in the UK: A scoping review' (a copy of this report is available on request)

The aim is to advance beyond existing knowledge.

- Discover any 'quality of life' indicators and metrics associated with other diseases or chronic illnesses that exist to allow for comparisons between different conditions and/or extended to include IBD. This comparative analysis could encompass both domestic and international perspectives, allowing for a comprehensive understanding of quality of life metrics.
- Identify any similar pieces of work by other organisations/charities.

2. Methodology Development for Indicator Creation

- In line with our preliminary insights into likely priority areas, develop a methodology for indicator development with a primary emphasis on **health and financial security** aspects, specific to people of all ages living with Crohn's and Colitis. Outline the process of selecting, refining, and validating the identified indicators, with due

considerations for different populations, recognising potential variations in experiences and perspectives.

- Identify any gaps in the data.
- Using the developed methodology, create a set of metrics and indicators within the financial security and health domains for Crohn's and Colitis, driven by patient outcomes. This should include assessing any relationships between different variables within the indicators.
- In recognition of potential data limitations, it is acknowledged that all the necessary data to populate the indicators may not yet exist.
- The chosen metrics and indicators need to be evidence based, validated, robust, reliable, relevant and meaningful.
- The indicators should be capable of being tracked over time to facilitate ongoing assessment and analysis.
- The data needs to be specific to people living with Crohn's and Colitis, with a primary emphasis on health and financial security aspects.
- Collection methods need to be robust.

3) Survey Design and Pilot

- Design and pilot a survey aimed at addressing identified gaps. Given the likelihood of having sufficient health data, the primary focus is expected to be placed on exploring financial security aspects.
- Ensure that the survey design aligns with the methodology developed in Requirement 2.
- The survey should be comprehensive, enabling the collection of relevant data and providing insights into the experiences of individuals living with Crohn's and Colitis.
- Validate and pilot the survey to assess its effectiveness, identifying and addressing any challenges or deficiencies in both the survey methodology and the data collection process.

As a reference point, we highlight the work of Carnegie UK, specifically their 'Life in the UK index' project evaluating collective well-being across social, economic, environmental, and democratic dimensions. This example highlights the type of comprehensive assessment we are seeking in understanding the varied experiences of individuals affected by Crohn's and Colitis. For more information on Carnegie UK [click here](#).

We recognise that this project is met with various unknowns, and we acknowledge the importance of flexibility and adaptability in navigating unforeseen challenges.

Furthermore, addressing gaps in missing data will be a key focus of future project work for the Quality of Life Dashboard. As our understanding evolves, forthcoming tenders will be initiated to explore additional indicators. These indicators will extend beyond the current domains of financial security and health, and will be drawn from the top ten list of impacts prioritised by our community.

This work 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](#).

Additional information:

The IBD Standards, published in 2019, set out what high-quality care looks like at every point of the patient journey, from pre-diagnosis, to surgery and ongoing care, as well as how IBD services should be organised to deliver this.

The IBD Benchmarking surveys serve as an evaluation mechanism for assessing service performance against the IBD standards. It includes a Service Survey, completed by individual IBD teams, and the IBD Patient Survey, completed by people with Crohn's and Colitis. The first set of benchmarking took place in 2019/20, which brought together the experiences of over 10,000 people with Crohn's and Colitis and 72% of IBD services across the UK. A new Benchmarking round took place in 2023 and reports are due out soon.

The IBD UK Benchmarking process is unprecedented as the most in-depth nationwide service assessment of IBD health care, and it is anticipated that this data will heavily contribute to the development of the Dashboard's indicators regarding health. **However, it is important to recognise that this data is not fully representative of the entire IBD community.** Consideration of this limitation is essential for interpreting the results and ensuring a nuanced understanding of the health indicators developed from this benchmarking data.

We have several commissioned projects that may contribute valuable insights to inform the metrics and indicators outlined in this tender:

- To understand the economic implications of living with IBD, we have commissioned a project aimed at calculating the lifetime financial impact of living with Crohn's or Colitis to the individual, to society and to the NHS. We are also examining the economic impact associated with delayed diagnosis.
- We are aware that currently we are not reaching everyone who is affected by Crohn's and Colitis in the UK. A recent epidemiology report by Nottingham University has provided a comprehensive understanding of how prevalent IBD is across different ethnicities, genders, socioeconomic groups and across regions throughout the UK. We commissioned targeted work to identify which social and economic factors have the biggest impact on people currently underrepresented in our research, including people who are Black, Asian, or of Mixed or Multiple ethnicities, and people from different socioeconomic backgrounds.

This commitment to inclusivity and a thorough understanding of the diverse impact of Crohn's and Colitis ensures that our research is not only comprehensive but also reflective of the varied experiences within the broader community. As we endeavour to develop metrics and indicators to measure quality of life, it is important that we aim to address the needs and challenges faced by all our community.

Detailed specifications

We expect the project to take **3-4 months** but are open to considering applications that would require slightly longer timeframes, if the justification for this is clearly shown.

We would consider the potential for academic publication, but we wish to use the results to inform our work in 2024 and academic publication must not delay this.

We welcome bids of up to **£40,000** for the whole project. Higher value bids may be considered if adequate justification can be given for the additional amount.

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.

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
- 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
7 th of February	Invitation to tender launched
9 a.m. on 6 th of March	Submission of tender
Week beginning 18 th of March	Interviews of shortlisted bidders
Week beginning 25 th of March	Award of tender
Week beginning 1 st of April	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 Rachel Ainley at research@crohnsandcolitis.org.uk by 6th March 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.