

Policy for Shaping Research

Background

We are regularly approached by researchers and organisations that are looking for people with Crohn's Disease or Ulcerative Colitis to help shape their research. Our research strategy supports research which reflects patient views and priorities and encourages and enables anyone who wants to get involved. Crohn's & Colitis UK help to offer opportunities for people who have been affected by Crohn's or Colitis to shape and guide research. Their involvement can provide an invaluable insight to researchers and their work.

It is the intention of Crohn's & Colitis UK to support requests to involve people affected by Crohn's and Colitis whenever possible. The following guidelines detail our criteria and the information we require; they also detail the obligations you have to people affected by Crohn's and Colitis who are involved in your work.

Eligibility for recruitment

Shaping research involvement opportunities submitted to Crohn's & Colitis UK for recruitment purposes are considered on a case by case basis by our research team. In your application you will need to show and provide the following:

- Participant information sheet
- The benefit of your research to people living with Crohn's and Colitis
- Direct relevance to our charitable aims and Research Strategy ([Crohn's & Colitis UK Research Strategy 2018-22](#))
- How you will communicate the outcomes of your work to participants and Crohn's & Colitis UK

Crohn's & Colitis UK will not accept any applications that:

- Involve or relate to Crohn's & Colitis UK endorsement of a treatment or product to people affected by Inflammatory Bowel Disease.

Undertakings

Researchers supported by Crohn's & Colitis UK will:

- Provide feedback on the number of participants recruited through Crohn's & Colitis UK so that outcomes can be measured
- Notify Crohn's & Colitis UK of research outcomes, relevant research publications or media releases.
- Provide feedback to all participants on how their input will be used, the progress of the project and the impact of their involvement.

Crohn's & Colitis UK will:

- Post generic social media posts on a bi-monthly basis linking people to our Shaping research opportunities webpage.
- Share opportunities to our research community.

Working with Industry

Crohn's & Colitis UK will accept opportunities from industry/pharmaceutical companies when it believes:

- Funding will benefit Crohn's & Colitis UK and people affected by Crohn's and Colitis.
- The company has followed the ABPI Code of Practice. Crohn's & Colitis UK will also comply with this [Code of Practice](#) according to clause 27 of the Code, 'Relationships with Patient Organisations'
- Crohn's & Colitis UK will also follow the [guidance for charities working with industry](#) by the Association of Medical Research Charities (AMRC)

We may require a written agreement to be in place setting out exactly what has been agreed in line with the code of practice.

Confidentiality

Crohn's & Colitis UK tends not to enter into Confidentiality Disclosure Agreements with organisations. We only request minimal information required as part of our vetting process. This is confidential and will not be disclosed outside of our research team at Crohn's & Colitis UK. The only information that will be made publicly available is that which you have provided for advertising purposes.

Financial contributions

- Crohn's & Colitis UK does not accept any payment for staff time required to provide support for participant engagement in research.
- It is best practice that participants are compensated for their time. Crohn's & Colitis UK would recommend the amount of compensation be in line with [INVOLVE National Standards](#).

Governance

- Crohn's & Colitis UK cannot take responsibility for any health or wellbeing outcomes arising from participation in shaping research opportunities advertised on our website or via social media or email.
- It is the researcher's responsibility to ensure full adherence to any relevant standards and ethics agreement is maintained.

Recognition of contribution

Crohn's & Colitis UK would appreciate acknowledgement to the contributions made by our organisation in supporting your work in any research outputs or wider communications.

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