Policy for Take Part in Research

Background

We are regularly approached by ***External Researchers*** (researchers not funded or working in collaboration with Crohn's & Colitis UK) who wish to access our members and other people with Inflammatory Bowel Disease (IBD) for recruitment into research studies. Our members have also highlighted a keen interest in "Taking Part in Research" motivated by the wish to take research forward. Our research strategy supports research, which reflects patient views and priorities, and encourages and enables anyone who wants to engage with research. We have hence created a **Take Part in Research** webpage for patients to find IBD research projects that they can potentially participate in. We believe our **Take Part in Research** initiative is especially important for those with IBD as the Royal College of Physicians (RCP) IBD audit showed that there are low levels of participation in IBD research.

Policy for Taking Part in Research

Research studies submitted to Crohn's & Colitis UK for recruitment purposes go through a thorough vetting process. Details are shown below:

Projects posted must have:

- Direct relevance to our charitable aims and research strategy (Crohn's & Colitis Research Strategy 2022-24)
- ***UK Ethics committee*** approval documentation
- A project protocol/summary detailing the peer review process completed
- Patient information sheet

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

- are for market research
- are being conducted by BSc level candidates and under
- suggest that Crohn's & Colitis UK is recommending a product to people affected by Inflammatory Bowel Disease
- are being funded by organisations or institutions from outside the UK

Undertakings

Projects supported by **Take Part in Research** will:

- provide feedback on the number of participants recruited through our Take Part in Research webpage so that outcomes can be measured
- notify Crohn's & Colitis UK of any relevant research publications

Generic posts will be made by the digital team on a bi-monthly basis linking people to the research studies and clinical trials on our “Take Part in Research” webpage.

Governance

This policy is approved by the Research Strategy and Funding Committee on behalf of the Trustees.

Crohn's & Colitis UK cannot take responsibility for any health or wellbeing outcomes arising from patients’ involvement in research posted on the 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.

Definitions and guidance appendix

External Researchers are defined as researchers who are not funded by Crohn’s and Colitis UK or who do not collaborate with us in co-funded research. These external research projects can be undertaken by non-commercial and commercial researchers.

Non-commercial researchers must be affiliated with a University, NHS Trust or accredited research institution which has agreed to sponsor their research.

Commercial research covers research undertaken by pharmaceutical, biotechnology and medical diagnostic companies. Where appropriate Crohn’s & Colitis UK will follow the AMRC guide for charities working with industry.

Ethics Committee approval

Crohn’s & Colitis UK expects all researchers embarked on research to consider the ethical risks of their work. Any project that is identified at the outset as requiring ethical review should be referred to your sponsoring organisation’s Research & Development (R&D) department. If they are unable to provide the level of necessary review, they will refer the case to the relevant external UK research ethical committee. Research undertaken by pharmaceutical companies are expected to follow the British Pharmaceutical Industry (ABPI) code of practice 2019, particularly clause 27 (working with patient organisations). We will require a written agreement to be in place setting out exactly what has been agreed in line with the code of practice.

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