CROHN'S & COLITIS UK

Research Strategy 2022-2024

Introduction

What we do

Crohn's & Colitis UK supports research for the benefit of people affected by Crohn's and Colitis in several ways:

- Funding research ranging from small grants to full programmes
- Working with others to drive research into Crohn's and Colitis
- Facilitating patient and public involvement (PPI) in research design and delivery
- Supporting people with Crohn's and Colitis to participate in clinical trials and studies
- Sharing research findings and translating findings into patient facing news items, blogs, reports, and information

Funding research

We've awarded research grants since 1979, funding over £11.5m of research. We fund medical research, and research to improve the lives of people with Crohn's and Colitis. We use a robust and impartial process accredited by the Association of Medical Research Charities (AMRC) to review applications and award grants. We can compare our research spend against other charities via the AMRC research expenditure dashboard (google.com). We published a report on our research funding impact in 2017, however demonstrating the impact of our funding programme to date is challenging and difficult to measure.

Patient and Public Involvement (PPI)

We support people with Crohn's and Colitis to shape and participate in research, which improves the outcomes of activities across the research funding cycle[1]. With our help, over 2,100 patients took part in or helped shape research from 2019 to 2020. We follow AMRC best practice standards on PPI and are working towards INVOLVE standards[2] .

We support research either via our *shaping research* offer (for studies in the early stages or that are yet to receive funding) or via our *taking part in research* offer (for studies recruiting participants). We support studies that meet our agreed criteria by disseminating information via our website, social media, or research involvement mailing list, and recruiting patients to be part of steering or advisory groups. Our staff and trained volunteer Research Champions also support research by reviewing materials and attending steering group meetings.

We also hold an annual PPI Day, which took place virtually in 2020 and 2021, with over 150 participants each year.

Researchers are required to demonstrate effective PPI when submitting funding applications, and demand from researchers for our support with PPI is steadily increasing.

We have identified that we need to do more to find out why some people engage in PPI and which groups are missing e.g., age, gender, ethnicity, and socioeconomic groups to ensure research participants accurately reflect everyone affected by Crohn's and Colitis.

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[1] The PIRICOM Study: (ukcrc.org)

[2] https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf

Research landscape

Key stakeholders for Crohn's and Colitis research include:

- Institutional funders such as the Wellcome Trust, National Institute for Health Research (NIHR), the Health Foundation, UK Research and Innovation, and Health Data Research UK (HDR UK)
- Association of Medical Research Charities (AMRC) of which we are a member
- Other IBD or gut charities – national and international
- Other charities with areas of mutual interest e.g., pain, immune disorders
- The pharmaceutical industry
- Clinical and academic researchers
- International funders of IBD research

And most importantly people living with Crohn's and Colitis and the healthcare professionals who deliver their care.

Research priorities for Crohn's and Colitis

The James Lind Alliance (JLA) brings patients, carers, and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 unanswered questions or evidence uncertainties that they agree are the most important. The aim of this is to make sure that health research funders are aware of the issues that matter most to the people who would benefit from the outcomes of the research The James Lind Priority Partnership Top 10 was published in 2015[3]. We know from listening to feedback from patients through our services, surveys and the IBD UK National Report that these areas are still key priorities today for people affected by Crohn's and Colitis.

In 2019 the British Society of Gastroenterology (BSG) guideline development group identified 20 research priority themes as part of their work to develop the consensus guidelines on the management of Inflammatory Bowel Disease in adults.[4]

In 2020, the Crohn's and Colitis Foundation IBD Partners network of 150,000 patients identified diet, complementary medicine, medications, mental health, autoimmune comorbidities, course of disease and cause of disease as patient priorities for research[5].

Some work has been done on progress against the James Lind Alliance top ten priorities[6] however we have identified that we need to gather further evidence and information on:

- What further work has been done since 2015 to address the James Lind Alliance IBD Top 10 priorities and other identified research priorities?
- Has our funding made a difference in these areas?
- How have other funders addressed the priorities to date e.g., the NIHR, Medical Research Council, Wellcome Trust, other charities, pharmaceutical companies?
- Are there new areas of priority for patients today?
- How do these priorities map to other priorities internationally and what progress has been made?

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[3] https://www.jla.nihr.ac.uk/priority-setting-partnerships/inflammatory-bowel-disease/top-10-priorities/

[4] BSG-IBD-Guidelines-2019.pdf

[5] https://www.crohnscolitisfoundation.org/blog/addressing-top-patient-concerns-through-ibd-research

[6] P123 Are we addressing the top ten research priorities in management of IBD in the UK? | Gut (bmj.com)

Drivers for change

External environment

The coronavirus pandemic is likely to have a long-lasting effect on clinical services and the availability and priorities for health research funding. In the short to medium term, we expect to see a sustained increase in national focus on infectious disease, and this will make competition for UKRI funding for IBD research more intense. This is happening globally – driven by COVID-19 - but it has also brought opportunities related to the immune system which could be relevant. While this is mostly focused on infectious disease response, it will include monitoring immune response in those at higher risk e.g., with underlying health conditions and using immune modifying medications, and this may bring further opportunities for partnership with other charities and organisations with an interest in this area. The response to the pandemic has demonstrated the value of partnerships between charities and others and there is increased awareness of the common issues faced by all that cannot be tackled by individual charities alone.

COVID-19 is also driving continued investment in data science, artificial intelligence (AI) and machine learning. Over the next few years, health data research is likely to become increasingly important[7] as significant UK national strategic investment bears fruit. Health data research combines maths, statistics, and technology to manage and analyse very large datasets across health and care systems. Investment by Crohn's & Colitis UK has positioned the IBD research community to benefit from national research investment. Crohn's & Colitis UK are partners in Gut Reaction, a HDR UK supported data project for IBD, and we are co-owners of the IBD Registry.

However, chronic disease remains a significant financial drain on the NHS and will be prioritised once the pandemic subsides. Concerns over delayed diagnosis and treatment backlogs due to the pandemic will drive further research into cost effective treatments and care pathways.

COVID-19 is not the only major driver of change. The Life Sciences Industrial Strategy[8] reshaped public sector investment in medical research in preparation for Brexit and will continue to do so. Overall, national investment in medical research is increasing, with major investments in a wide array of areas relevant to IBD, including but not limited to the Accelerating Detection of Disease programme[9], and the new Rosalind Franklin Institute[10] focused on breakthrough technologies to accelerate the pace of new treatment discovery.

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[7] UK government to fund £37M into data-driven initiatives | Healthcare IT News

News: NIHR welcomes new vision for the Future of UK Clinical Research Delivery | NIHR

New programme to explore how innovation in health data can benefit everyone (wellcome.org)

The Grand Challenge missions - GOV.UK (www.gov.uk)

[8] Life sciences: industrial strategy - GOV.UK (www.gov.uk)

[9] https://www.ukri.org/our-work/our-main-funds/industrial-strategy-challenge-fund/ageing-society/accelerating-detection-of-disease-challenge/

[10] https://www.rfi.ac.uk/about/

Nutrition and the microbiome are also growing areas of research interest with relevance to IBD[11].

Long term trends in biomedical science mean that the costs of research continue to increase, as does the concentration of funding into a few large centres with international reputations receiving major funds from big investors. This means that for smaller funders like Crohn's & Colitis UK it is less likely that our grants will be able to support research teams. However, there are opportunities where charitable investments could be used to match IBD patient priorities to national research investment. There is also a commitment to support research across the NHS more broadly[12].

The UK clinical trial landscape is world leading which drives opportunities for international funding in IBD research. Clinical research networks have been established in each of the four UK nations funded by the UK Health Departments. Together these national networks form the UK Clinical Research Network (UKCRN)[13], strategic oversight for which is provided by the UKCRC.

Areas of opportunity

Horizon scanning suggests that future opportunities may include:

- Continued rapid growth of health data research
- AI and technology - digital health is growing rapidly but how does this translate into clinical practice and improved patient care/experience?
- A greater appetite for collaboration - working with those with interest in immune research[14] with improved understanding of disease mechanisms which could lead onto new diagnostics or treatments
- Working with other stakeholders who support those living with chronic disease around areas of shared patient experience
- The UK clinical trials space - the government have set out their vision for the future of clinical research delivery[15][16] which includes a drive to encourage the NHS to make research part of effective clinical care, ensuring participating in research becomes more accessible and supporting research in more diverse and underserved communities.

Internal environment

The previous Crohn's & Colitis UK Research Strategy was published in 2018 when we anticipated continued growth in our income. However, the impact of the COVID-19 pandemic, the subsequent fall in our income and increased demands on our services, have meant that the strategy required an earlier review. It is anticipated that income may not return to pre-pandemic levels for several years and even then, it is key to ensure that we

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[11] Transforming nutrition science for better health (wellcome.org) , Home - Periodic Table of Food Initiative (foodperiodictable.org)

[12] https://www.nihr.ac.uk/about-us/our-mission/our-mission-and-strategic-workstreams.htm

[13] https://www.ukcrc.org/research-infrastructure/clinical-research-networks/uk-clinical-research-network-ukcrn/

[14] https://jdrf.org.uk/connect-immune-research/

[15] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/568772/dh_4127152_v2.pdf

[16] https://www.gov.uk/government/news/uk-government-sets-out-bold-vision-for-the-future-of-clinical-research-delivery

continue to deliver the maximum impact possible from our investment of time and money into research.

We have reviewed the 2018 Crohn’s & Colitis UK Research Strategy and sought expert input and advice from our research strategy advisers, our Research Strategy and Funding Committee and other stakeholders, and concluded:

- The current strategy is very broad given the funds available, the size of the team and our income
- We may achieve more impact with a less frequent call with a larger award and more focused funding with strategic investment in priority areas and/or build portfolios in particular areas
- Collaborative networks – our first collaborative network, the Pain Collaborative Network, has had success in bringing researchers and stakeholders together to increase understanding and drive funding for research from others with larger funds available. Leveraging funds in a similar way in the future will help increase our impact
- Patient and public involvement – we are receiving increasing requests to support with patient and public involvement; however, this involves significant resource. It is important to consider whether this should be funded by a patient charity such as us when some organisations, e.g., pharmaceutical manufacturers, have significant resources to spend on this area. A tiered model of support may be more appropriate
- Our previous research strategy does not explicitly support our wider strategic aims including our campaigns, policy, and services
- Career development support for IBD researchers – the needs for this support and the impact of a patient charity providing career development support is unclear. The investment required is significant and other sources of funding and support exist. This is an area where other stakeholders, including the BSG, Academy of Medical Sciences, the NIHR and others may have more of a role. Supporting participation of clinicians in research is a priority in the BSG strategy 2021-24[17].

Aims of the research strategy

The research strategy should drive change in those areas that are most important to people affected by Crohn’s and Colitis and should:

- ensure patients are at the centre of IBD research
- deliver on the aim of driving pioneering research for patient benefit
- improve the evidence base to support patient care and other charity workstreams e.g., meeting evidence gaps to support policy and advocacy work
- align with recommendations and priorities for improving patient care e.g., the recommendations from the IBD UK national report 2021[18]

It is key that the research strategy aligns with and supports our vision, mission, and strategic aims. The charity strategy is also being reviewed in 2021.

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[17] Introducing the BSG Research Strategy 2021-2024 | The British Society of Gastroenterology

[18] IBD UK National Report 2021

Strategy 2022 - 2024

Our vision and the three key domains

Our research mission and vision

We drive pioneering research to achieve improved lives today and a world free from Crohn's & Colitis tomorrow

- Directly funding research
- Increasing investment by others in IBD research
- Patient and public involvement

November 2021

Domain 1 – Funding research

The ambition

We will ensure that our funding for research delivers the maximum impact possible with the resources we have available and drives further future investment by others in improving lives or finding a cure for people affected by Crohn’s and Colitis.

Key elements

- A new approach to funding – moving away from an annual open call to a more strategic approach to achieve clear and specific outcomes
- Targeting funding to meet key priority areas that are important to patients
- Funding that supports and enables larger investment from other funders including funding internationally (if linked to UK partners) or leveraging international funding
- Funding areas that are unique to Crohn’s and Colitis where others are not funding and addressing unmet need
- Maintaining an awareness of other funding in IBD to avoid duplication
- Funding that drives or stimulates innovation in clinical practice
- Funding research that supports our charity aims to improve equality, diversity, and inclusion

What will success look like?

A sustainable programme of research funding that delivers maximum impact against the research priorities as identified by patients.

How will we measure and monitor impact?

We will use recognised tools to measure:

- Publications
- Evidence of change in clinical practice
- Evidence of policy change
- Evidence of progression to future funding

Domain 2 – Increasing investment in IBD research

The ambition

We will be leaders in influencing and supporting others to drive increased investment in research on areas affecting people with Crohn's and Colitis. We will build networks and partnerships to ensure that Crohn's and Colitis is included in all research into areas of common patient experience.

Key elements

- Develop a "state of the nation" report on the current IBD research landscape both in the UK and internationally
- Grow and support the Pain Collaborative Network to leverage new funding and support
- Identify and establish a new Collaborative Network for one of the other areas in the JLA Top 10
- Map and influence to drive research against the JLA Top 10 priority areas
- Establish networks for thought leadership, supporting collaborations and partnerships within the research community, academia, government, and industry
- Develop a collaborative relationship with the NIHR to jointly progress IBD research priorities
- Identify and work with other charities with areas of common patient experience
- Build relationships and partnerships to drive increased international research into Crohn's and Colitis
- Support applications to other funders

What will success look like?

- Increased investment year on year in IBD research with new and existing funders for IBD research and progress against the JLA Top 10 priority areas
- Evidence that Crohn's and Colitis is included in large studies into areas of shared experience including pain, fatigue, and impacts of chronic disease
- Effective and active collaborative networks that are successfully obtaining funding from others.

How will we measure and monitor impact?

- Progress against the JLA Top 10
- UKCRC portfolio analysis shows increased spend on IBD research
- Evidence of networks leveraging new funding into priority areas

Domain 3 – Patient and Public Involvement in Research

The ambition

We will ensure that patient and public involvement by people affected by Crohn’s and Colitis is embedded in all research into areas that are directly or indirectly relevant to people with Crohn’s and Colitis.

Key elements

- Improve diversity, ensuring that patients and the public involved in research reflect the diversity of the Crohn’s and Colitis community
- Ensure charity resources are used appropriately to support patient and public involvement by developing a tiered approach to the support we offer
- Develop other ways to support PPI and engagement e.g., guidance and resources for researchers working with people affected by Crohn’s and Colitis, establishing PPI networks
- Grow our networks of research active patients and Research Champions
- Increase the number of active Research Champions, developing a programme of training and support for patients involved in research

What will success look like?

Evidence that active and engaged people affected by Crohn’s and Colitis are able to influence and shape all research affecting people with these conditions.

How will we measure and monitor impact?

- Numbers of people engaged in research
- Diversity of PPI participants
- Numbers of trained and active research participants
- Capturing feedback from researchers and participants
- Case studies of involvement activities.

Appendix

Appendix 1- References and useful resources

- AMRC strategy
- NICE strategy
- James Lind Alliance IBD top 10 priorities
- Future of UK clinical research delivery (Gov UK)
- NIHR strategy
- BSG research strategy
- EFCCA
- Crohn’s and Colitis Foundation (US) strategy

Appendix 2 - stakeholders and consultation

The following stakeholders have been consulted during the development of this strategy:

- People affected by Crohn’s and Colitis
- Crohn’s & Colitis UK staff and Trustees
- Crohn’s & Colitis UK Research Strategy and Funding Committee (RSFC)
- Bowel Research UK
- Guts UK
- IBD UK member organisations:
    - British Society of Gastroenterology (BSG) - IBD Section and CRG
    - The Association of Coloproctology of Great Britain and Ireland (ACPGBI)
    - British Association for Parenteral and Enteral Nutrition (BAPEN)
    - British Dietetic Association (BDA)
    - British Society of Gastrointestinal and Abdominal Radiology (BSGAR)
    - British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)
    - Children with Crohn’s and Colitis (CICRA)
    - Ileostomy & Internal Pouch Association (IA)
    - IBD Registry
    - The Primary Care Society for Gastroenterology (PCSG)
    - Royal College of General Practitioners (RCGP)
    - Royal College of Nursing (RCN)
    - The Royal College of Pathologists
    - Royal College of Physicians (RCP)
    - Royal Pharmaceutical Society (RPS)
    - Clinical Pharmacy Association (UKCPA)

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