IBD Registry - Achievements in Numbers

We're proud of the achievements of the IBD Registry since we were launched as an independent company in 2018:

- re-launch as a research database
- enabling research and studies for better outcomes
- supporting clinical teams to understand their quallity of care
- working in partnership

We want to thank everyone who has shared our journey with us! We couldn't have done it without you.

All data points as at end of December 2023 unless otherwise stated

Registry as an ethically approved database – the 'new' registry

In July 2022, the IBD Registry relaunched as an integrated research and healthcare improvement database, with approval from the Health Research Authority (HRA) to be a research ethics database. This meant that where a person with IBD had consented for their data to be used for research using the HRA-approved consent form, their data could be used across multiple research projects, speeding up the research process and bringing benefits to patients faster. This followed our three year transformation as part of the 'Gut Reaction' programme, funded by Health Data Research UK, which included also changing the way we captured data so it could link, if approved, with other databases such as the NIHR BioResource.

1 database	One unified re-usable database supporting both research and quality of care improvements, collecting longitudinal (ongoing) data on IBD at the point of clinical care, following the patient's care journey
70 hospitals	Individual NHS hospitals submitting data to the 'new' registry in 2023, either as an NHS Trust, a combined IBD service or an individual hospital site
5,380 patients	People with IBD who consented to the IBD Registry's new research consent in 20 months (that's approximately 250 people signing up, every month, since May 2022)
30,943 journeys	Individual patient care journeys currently being followed, with thanks to all our clinical contributors
302,919 events	Care and treatment events captured for the 30,943 patients on their journey

Supporting research and studies that improve the lives of people with IBD

The IBD Registry uses its data and tools to support research and studies that lead to better outcomes for people with IBD. We began indirectly, by supporting projects with tools and data collection. Since we re-launched as an ethically approved

database in 2022, we have focused on accelerating clinical research, by re-use of the data we hold, and by clinical research leadership, to re-use our know-how.

1 research accelerator	In 2023, the IBD Registry started the 'BISCUITS' project (Biological Agents Sequencing in Clinical Units as a research exemplar for effective and efficient research. This will complete in 15 months, including 2 abstracts presented at scientific conferences, and a research paper to follow.
22 hospitals	NHS hospitals that the IBD Registry supported as part of the 'VEST' vedolizumab study, run by University Hospital Southampton
32 publications	The IBD Registry has contributed to 32 papers and presentations (you can see the full list here)
35 hospitals	Number of NHS hospitals that the IBD Registry supported as part of the 'PINPOINT' paediatric (children) study, run by University of Edinburgh
92 adverse events	Number of adverse events captured by the registry's separate drug safety monitoring project (phase 4 clinical trials)
149 IBD services	Number of IBD services participating in the IBD UK 2023 Benchmarking survey, delivered on the IBD Registry platform
9,426 patients	People who used the COVID-19 Risk Tool who then consented to the same data being used more widely for specific research purposes
15,198 patients	Number of patients participating in the IBD UK 2023 Benchmarking survey, delivered on the IBD Registry platform

Supporting clinical teams in their Quality of Care assessments

Clinical teams have submitted data to the IBD Registry to build a picture of the care people with IBD receive. In return, the IBD Registry analysed the data for each hospital, benchmarked against national data, and provided this back to participating clinical teams. A particular focus of data collection and reports has been the safe use and monitoring of advanced therapies (biologics and small molecule immunomodulators). Since 2018, the data has shown monitoring was sustained despite the disruption of COVID-19 and steady improvements in pre-treatment safety screening occurred.

5 national audit reports	A report each year (2019-now) describing progress in the national audit of biological therapies in IBD, hosted by the IBD Registry
6 years	The number of consecutive years (2018-now) that the IBD Registry was appointed by NHS England to be the lead for IBD on the Quality Accounts register
900 bespoke reports	More than 60 individual NHS hospital benchmarking reports provided each quarter to participating clinical teams (2018-now)

COVID-19 Risk Tool

At the start of the COVID-19 pandemic in March 2020, the Government announced the COVID-19 shielding programme, and asked the NHS for lists of people, including those with IBD, who might need to be assessed as to whether they were at greater risk from the virus. The way that the NHS held data meant that no-one had these lists. We built and launched a patient-friendly self-assessment risk tool to reassure patients and support hospital IBD teams, working in partnership with key stakeholders. This was more than a data collection survey - with the patients' permission, we returned to each hospital 'their' patients' data, so the IBD team knew who was at risk.

3 awards	The number of prizes awarded for the Risk Tool. These were the Health Service Journal Award; Health Data Research UK; and Communique Healthcare Communications
8 days	Number of days to design and build the Risk Tool ready to launch on the 1st April 2020.
174 hospitals	Number of NHS hospitals who received lists of their patients at risk, so they could contact them as priority
27,605 logins	Number of people who logged onto the Risk Tool in the first week of April 2020 (at that point 16,541 had also completed it)
41,000 patients	People with IBD who used the COVID-19 Risk Tool between launch and the end date of April 2022.

Working in partnership and collaboration

The IBD Registry ran a data eco-system, only made possible by working in collaborative partnership with a range of stakeholders and partners.

3 founders	Our founding parent organisations were the Royal College of Physicians, British Society of Gastroenterology and Crohn's & Colitis UK
5 tools	Number of data tools provided for clinical teams to collect and manage data
6 partners	Consortium members of the HDR UK 'Gut Reaction' 3 year programme
17 sponsors	Number of organisations in the pharmaceutical and life sciences sector who supported us with grants and/or sponsorship between 2018 and 2023.
98 NHS Trusts	Number of NHS Trusts signed up since 2022 who wanted to start submitting data to the 'new' registry
Estimated at **60,000** patients	The people with IBD who participated in the IBD Registry, whether by consenting to research, completing a data survey, or taking part in the Risk Tool. Much of the data was collected anonymously, so we don't know exactly how many people it was - some may have participated in more than one tool. It could over 100,000 - the total

	number of participants added up across all the different types of engagement

Original data collection tool – the 'original' registry

The IBD Registry initially collected anonymised data on people with IBD, working with NHS Digital. We ran this database until April 2022, when the 'new' Registry database took over and this database was 'frozen'. The change to the new database was a key part of our 'Gut Reaction' change project, in order to align with the new NHS data landscape and maximise the contribution that the data that we hold could make to research and care studies.

25,420 consents	Patients who consented to the original registry database
85,986 patients	Individual patient healthcare journeys tracked within the original database, collected by NHS Digital