CROHN'S & COLITIS UK

Q & A with Mark Avery and Gut Reaction Team

Questions	Answers
I think there are ethical issues regarding "industry based" research, where commercial profit is an important and sometimes one of the main outcomes of the research. Is it not possible to conduct research through public institutions?	Health research is supported through many organisations (public and private) working with the NHS. Preventing commercial research and development (R&D) would limit innovation and slow or even prevent the development of new treatments. It is an essential part of bringing new products/treatments/services into use. Drugs and medical devices (e.g. for diagnostics), in fact almost everything used in the NHS apart from people, is made possible with investment from industry and developed by industry scientists. Industry also brings the scale needed to develop and manufacture drugs to the required quality and quantity. There is some good information on the understanding patient data website on exactly this point – see https://understandingpatientdata.org.uk/companies
Can you explain what the IBD BioResource is?	The IBD BioResource is part of the wider National Institute for Healthcare Research (NIHR) BioResource who work with participants who wish to support health research to provide rapid, consistent and valuable integrated access to samples, data and resources to tackle healthcare challenges. This short (3 minute) video gives a great overview of what it means to get involved. https://www.youtube.com/watch?v=BR0mvJh7Cxk

	The focus of the IBD BioResource is to expedite research into Crohn's Disease and Ulcerative Colitis and help develop new and better therapies.
Where/how would we have consented to our health record being used for research? Individually by our hospital, or generically e.g. via the NHS app? (Because I would have given individual consent but have opted out of the NHS data-grab of GP records via the NHS app)	All participants in the NIHR BioResource have given what we term 'explicit informed consent' to take part. In other words, participants must opt-in and give their approval to take part. You can find more information at https://bioresource.nihr.ac.uk/recruiters/consents/ If you have enrolled in the NIHR BioResource this would most likely have been at your hospital as part of a 1:1 conversation with a research nurse to understand what is involved, and then a form is signed. Patients can withdraw by phoning or emailing the BioResource at any time.
Is there something we can do to prompt being asked by our hospital team to participate in research, or to put the hospital forward as one which could take part?	You can ask your team about the BioResource at your next outpatient appointment, but even if your hospital is not currently part of the IBD BioResource there are other ways to support health data research into IBD (links below) BioResource: https://bioresource.nihr.ac.uk/participants/join-the-bioresource/ or the UK IBD Registry: https://ibdregistry.org.uk/
For me there is a concern about how my data is handled, whether it is properly de-identified etc. But this applies whoever uses it (industry or academia).	Understandable – transparency is important. 'The right to be informed' is a legal right under the General Data Privacy Regulation (GDPR) which states, "The principle of transparency requires that any information or communication relating to the

	processing of personal data is easily accessible and easy to understand, and that clear and plain language be used." All NHS organisations will have a privacy notice on their website that will tell you how your data may be used. Privacy notices for the NHIR BioResource, and UK IBD Registry can be found here: https://bioresource.nihr.ac.uk/about-us/governance-and-ethics/privacy-notice/ https://ibdregistry.org.uk/privacy-policy/ In terms of the work being done by Gut Reaction, there are a number of safeguards protecting people's data in place. The data are stored at specialist facilities, with significant commercial and technical expertise in data protection. Researchers must go through a thorough application process before they can access patient data. They can only access de-identified data; this is where any information that could link the data to an individual such as birth date or NHS number has been removed. Specialist technology firms, including Privitar, Aimes and Microsoft are partners in Gut Reaction to ensure that this is done to the highest standard.