



IBD BioResource

Newsletter

February 2019



National Institute for
Health Research

Our motivation


In the UK, over 300,000 people live with Crohn's disease (CD) or ulcerative colitis (UC), collectively known as inflammatory bowel disease or IBD. As people who have IBD are all too aware these conditions are characterised by debilitating abdominal symptoms, and, in their severe forms, have a major adverse impact on health and quality of life. We, the IBD BioResource, want to facilitate quality IBD research by groups around the UK so that current and future patients can benefit sooner.

Our strategy

- To create a national platform recruiting patients with IBD
- To generate detailed genetic and outcomes data and make this available to the research community in anonymised form
- To enable recruitment of patients for future research projects based on their genetic and clinical characteristics

Our target

Our goal is to recruit a very large panel of at least 25,000 patients with Crohn's or colitis (Main cohort) as well as 1,000 newly diagnosed patients (Inception Cohort) – all with clinical data and on whom we will generate detailed genetic data.



"Translating
today's science
into tomorrow's
treatments"

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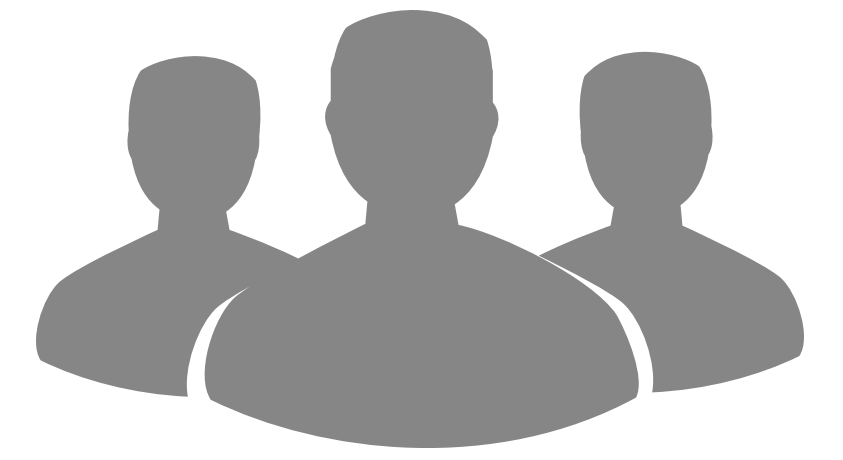
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IBD BioResource

Meet the team



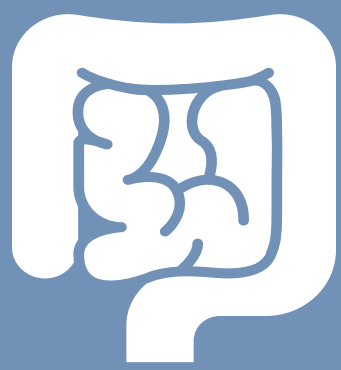
A warm welcome from Dr Miles Parkes, chief investigator of the IBD BioResource



Welcome to our first IBD Bioresource newsletter – and a brief apology that it has taken us a while to get this out. As you will see in the contents, our fantastic IBD Bioresource team have been hugely busy getting the project to ‘take off’ speed across the UK and ensuring that it can deliver on our mission. We are more than aware that some of you signed up to the project many months ago, and doubtless some will even have forgotten about it.

For you all I hope that this newsletter reassures you that the project is on-track and beginning to function as we wanted. Over the coming months you WILL be contacted about ‘stage 2’ studies being lead by different investigators around the UK, and I really hope that you are happy to help with some of these. By enabling this partnership between researchers and large, well characterised groups of patients we truly hope that the IBD BioResource can drive important research advances and help win the battle against Crohn’s and colitis in the years ahead. Our thanks to you all!

Research coordinators



Mrs Rachel Simpkins has been working for the IBD BioResource since January 2016. Research interests include new therapies in gastrointestinal disease and the genetic basis of Crohn’s disease and ulcerative colitis. Her day to day work focuses on managing the Inception cohort of newly diagnosed patients.



Mrs Cathy Thorbinson joined the IBD BioResource team in July 2017 following 10 years in the field of Oncology clinical trials and studies. Routine work now includes regular site initiation visits to various hospitals around the country along with her colleagues and ensuring timely recording of samples collected at those sites, liaising with the busy nursing staff to help with problems and finally to encourage recruitment at sites.



Dr Laetitia Pele joined the IBD BioResource team in January 2018. Prior to her appointment, she spent the previous 12 years as an investigator scientist researching the effects of dietary nanoparticles on intestinal health. In addition to Research facilitation and coordination, Laetitia has a strong passion for knowledge transfer through visual and written communication.

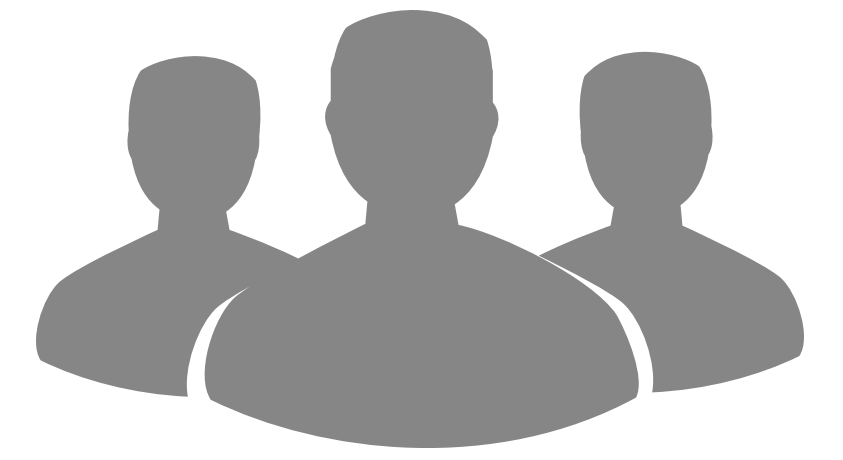


Dr Deepthy Francis joined the IBD BioResource team in February 2018. Prior to her appointment, she undertook a PhD in Cell, Molecular Biology and Genetics and worked as a Data Manager for the Cambridge Cancer Trial Centre. Deepthy's main interests lie in Scientific research that benefits the public and helps to improve the quality of life of patients in innovative ways.



IBD BioResource

Meet the team

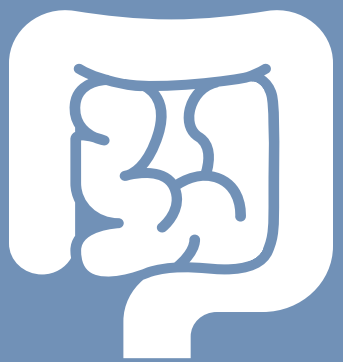


Recruitment administrators

Last December we were very sad to say goodbye to one of our recruitment administrator, Mrs Hannah Cheesman. We want to express our deepest thanks for being such a great team member and for all the hard work she provided. We wish Hannah all the very best in her new endeavours in the Mental Health Sector for Children and Young people.



Miss Francesca Muldoon joined the IBD BioResource in February 2017. Prior to this she worked across a range of administrative roles in Cambridge Assessment, from exam marking to the Historical Records Department. Outside of work Francesca loves spending time with her whippet, Buddy. She enjoys crafting and has recently turned her hand to pottery.



Miss Edith Kaze joined the IBD BioResource team in January 2018. Prior to her appointment, she was working as an Adviser for the Modern Slavery Helpline. In addition to this, Edith has worked in a range of administrative as well as care giving roles in the NHS for a number of years. She has also worked for international organisations focused on community-based trauma healing work, peace and reconciliation and sustainable livelihoods.



Mr Jonathan Mitchell has been part of the IBD Administration team since December 2017, becoming a permanent member of staff in January 2019. Prior to this, he worked across a wide range of roles within the NHS and Pharmaceuticals industry. Jonathan has a passion for visual media, having curated and written for the Cambridge Film Festival, as well as writing on African films, post-colonialism and documentary films.

Data manager



Mrs Rasha Shawky joined the IBD BioResource team in January 2016. Prior to her appointment, she spent the previous 15 years working for software development companies. Rasha has great interest in data engineering, solving problems and answering questions using data.



IBD BioResource

Progress so far



Main cohort

The Main cohort comprises individuals with established CD and UC. Both clinical data (surgery, macroscopic extent, medication and co-morbidities) and self-reported phenotypes (IBD and general health questions and family history) are collected, alongside plasma, serum and DNA samples. The latter are undergoing Whole Genome Sequencing at the Wellcome Trust Sanger Institute.

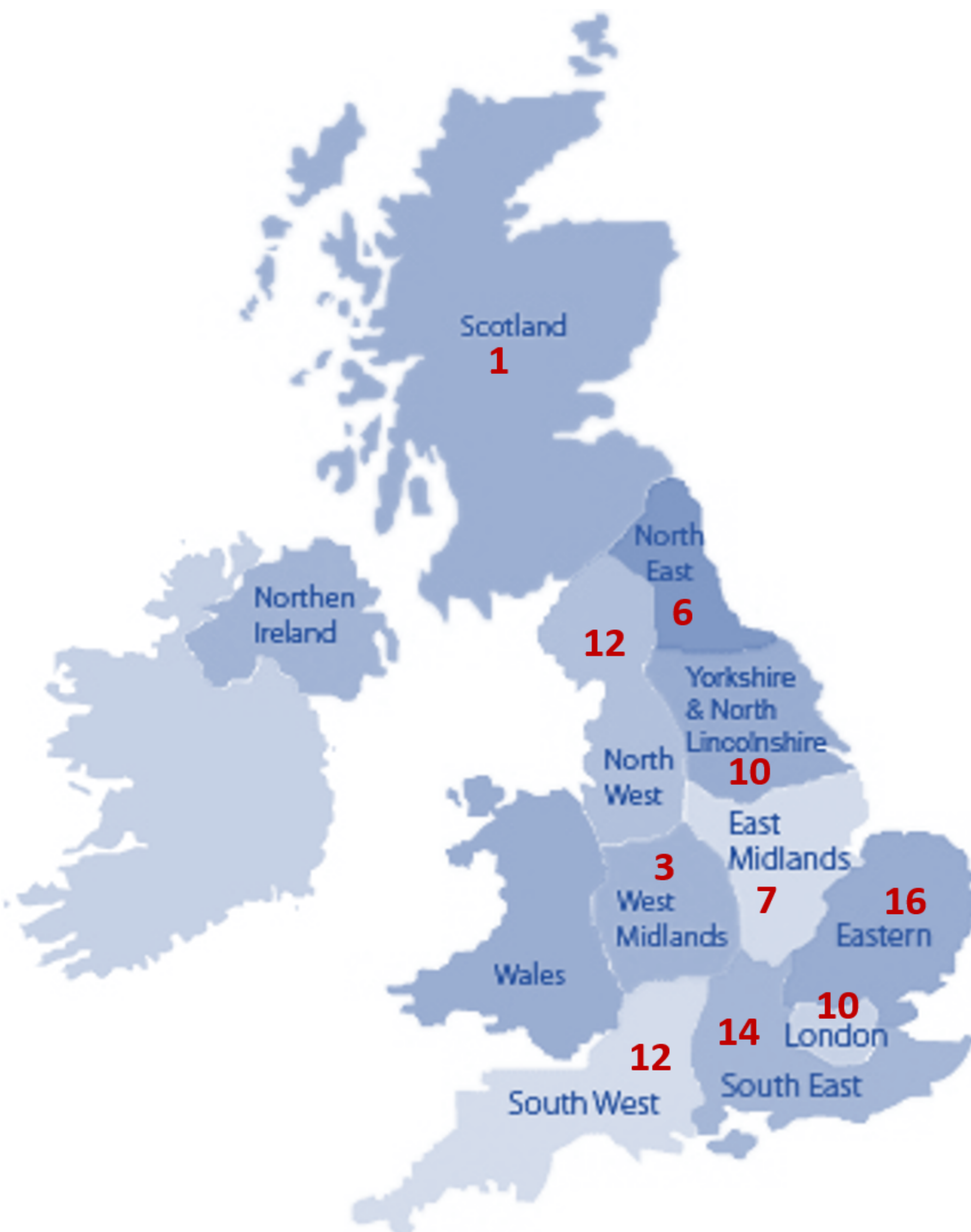
We now have 91 sites open and recruiting and a further confirmed 12 sites will be set up during the course of 2019 (including 2 in Wales). We are also very excited to have set up our first site in Scotland, which is being led by Dr Charlie Lees and his team at the Western General Hospital, Edinburgh. Hopefully more Scottish sites to follow!

Volunteer recruitment is still going strong and we now have over 20,000 patients enrolled into our IBD BioResource panel.

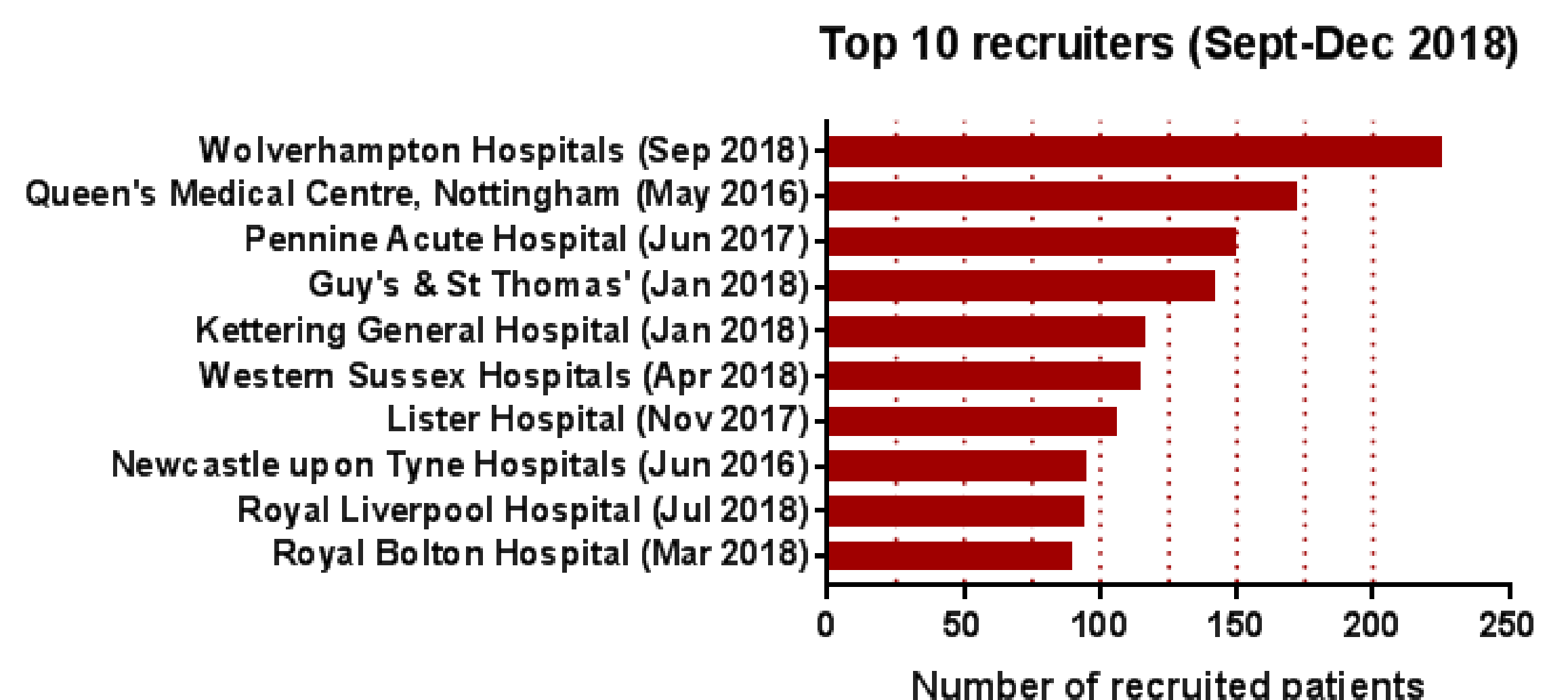
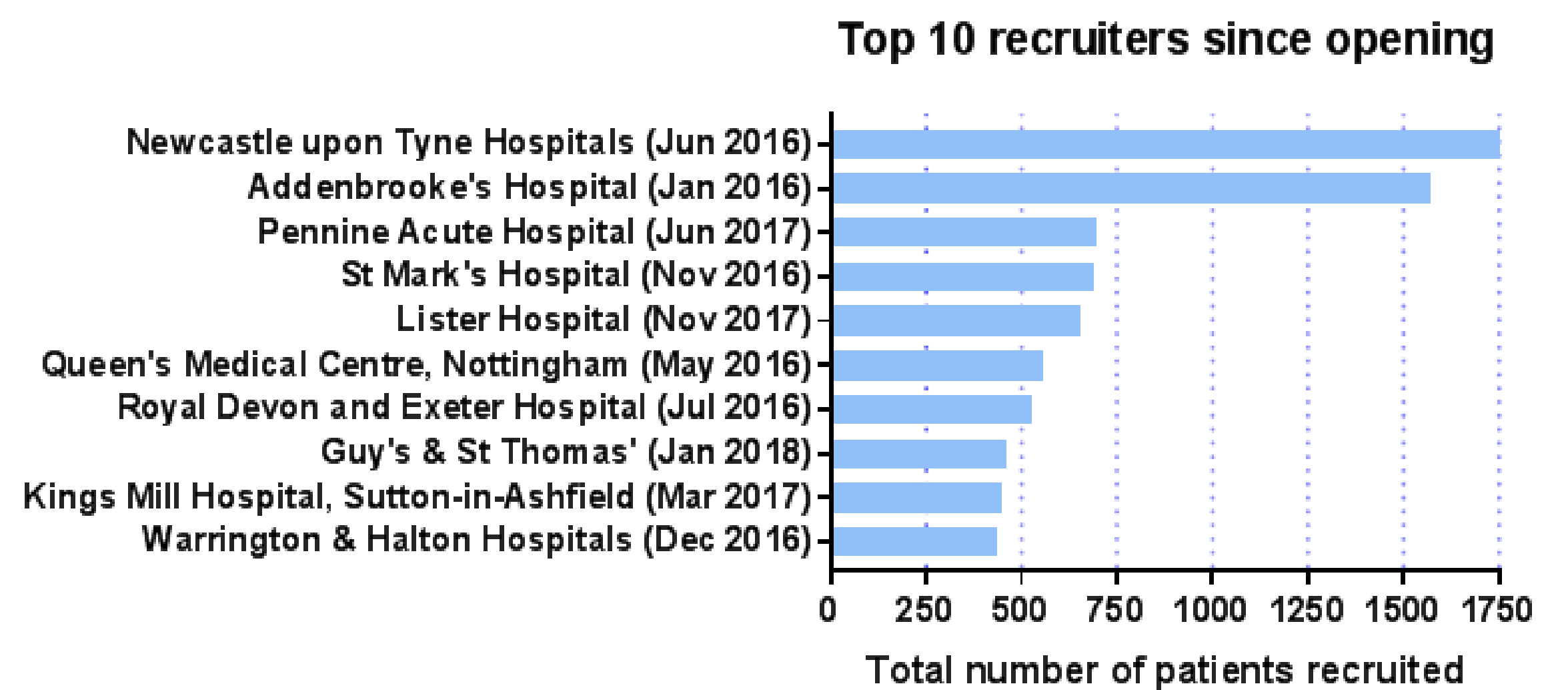


Thank you so much for being part of our ever expanding IBD BioResource network! We are very grateful.

Site map



Top 10 recruiters





IBD BioResource

Progress so far



Inception cohort

The aim of the Inception cohort is to recruit 1,000 patients who are new to their diagnosis of Crohn's or colitis and follow them for up to 3 years through a combination of sample and clinical data collection. This includes stool, biopsy tissue and whole blood for RNA.

This cohort offers a unique resource to undertake 'omics' studies and facilitate research into determinants, predictors and biomarkers of IBD disease course and treatment response

The Inception cohort has now been up and running fully since March 2018 and to date 38 sites have been trained to identify and recruit these patients. Recruitment has been going well, but of course to achieve the goal of 1,000 patients we will need to train teams in more sites.

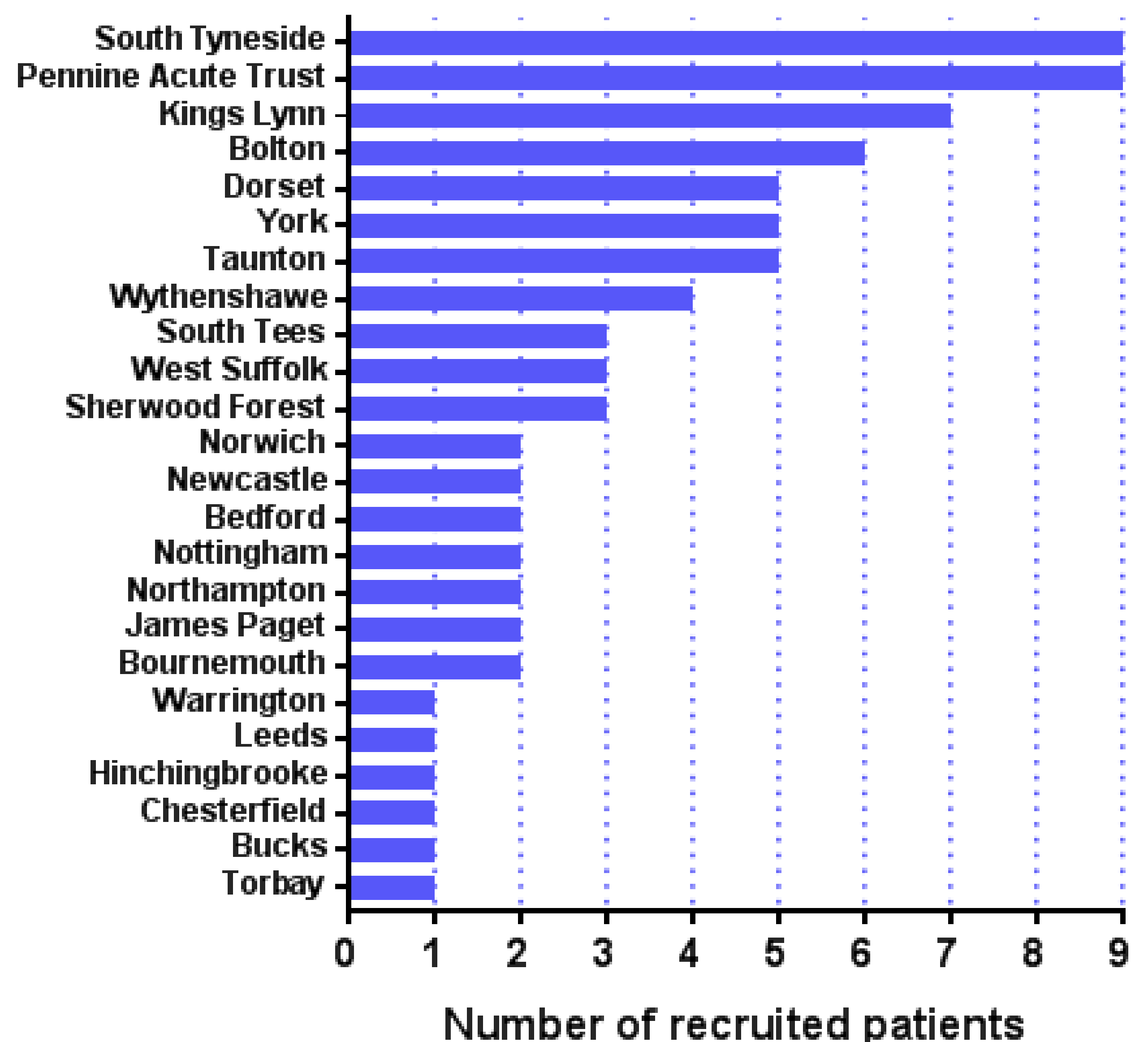


We only require a minimum recruitment of 5-10 patients per year at each site

Site map

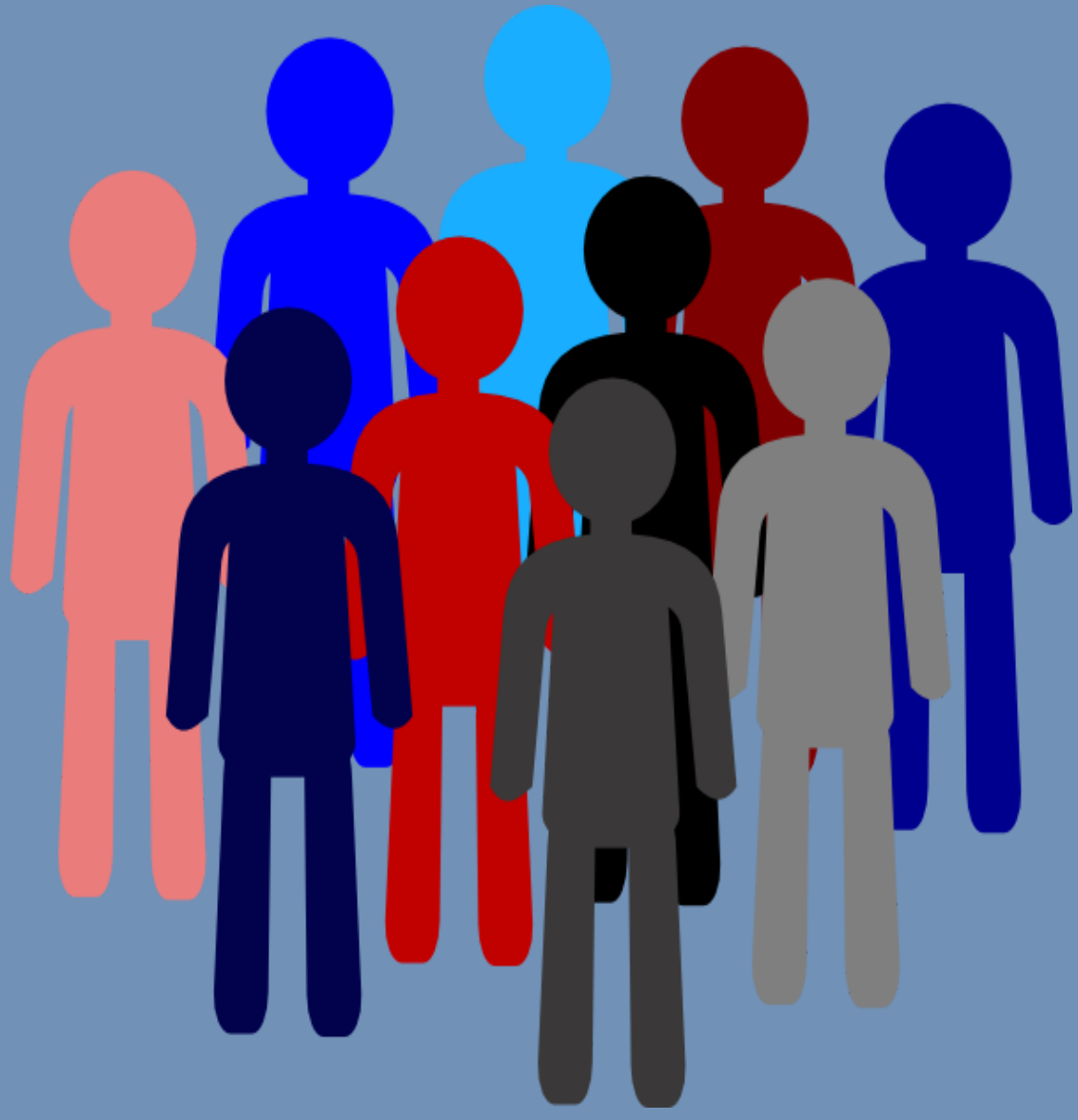
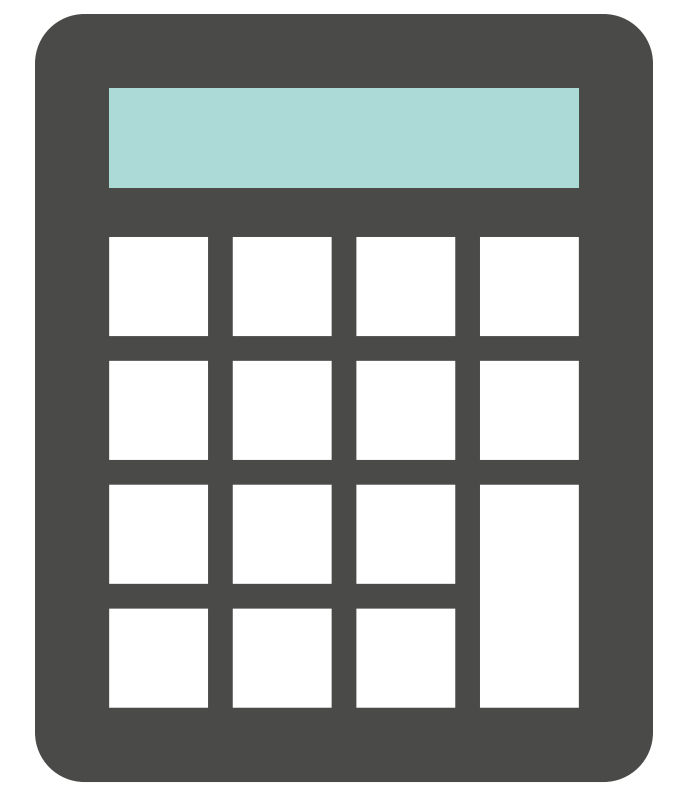


Recruitment per Site





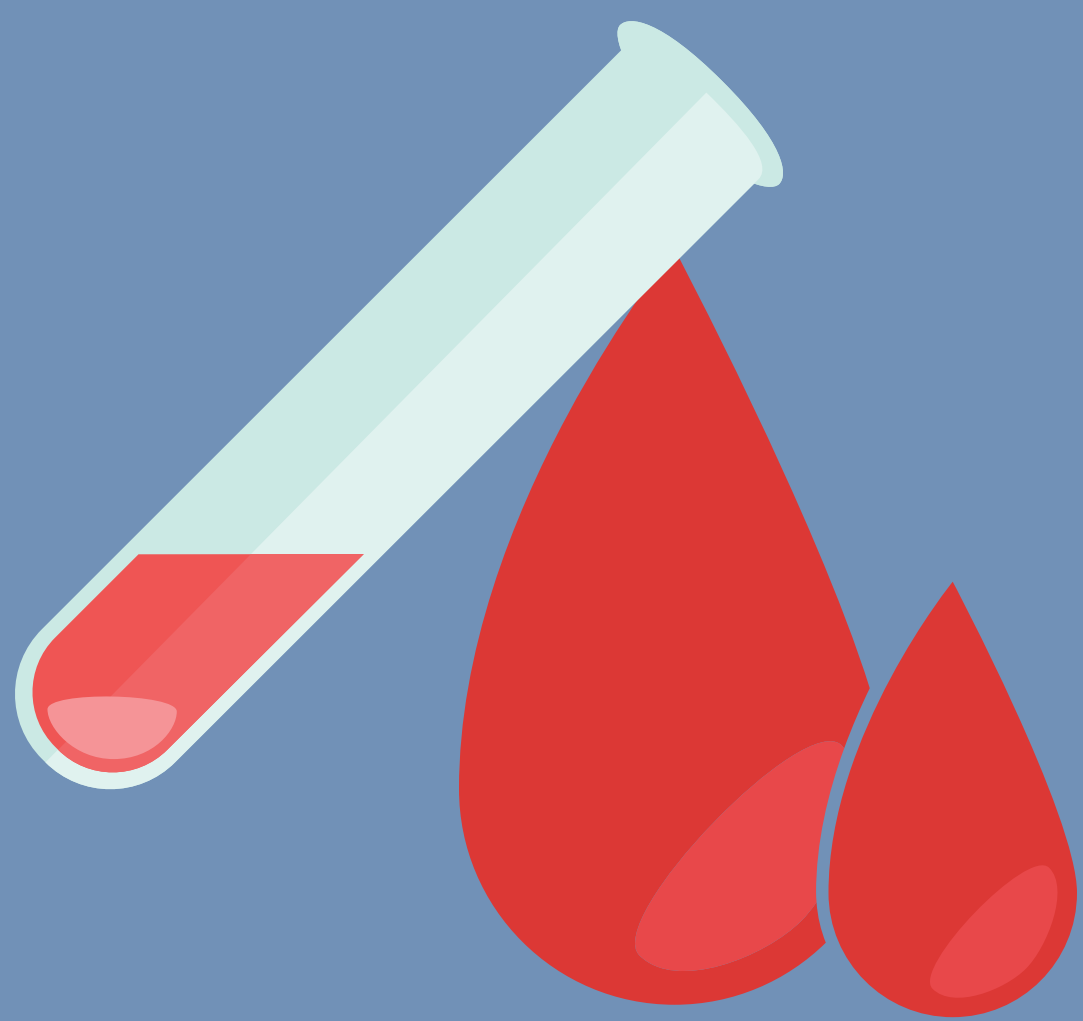
IBD BioResource in funny numbers!



Since 2016, we have recruited **over 20,000** participants into the IBD BioResource ...

OR

...the equivalent of the **whole population of Newmarket, Suffolk**

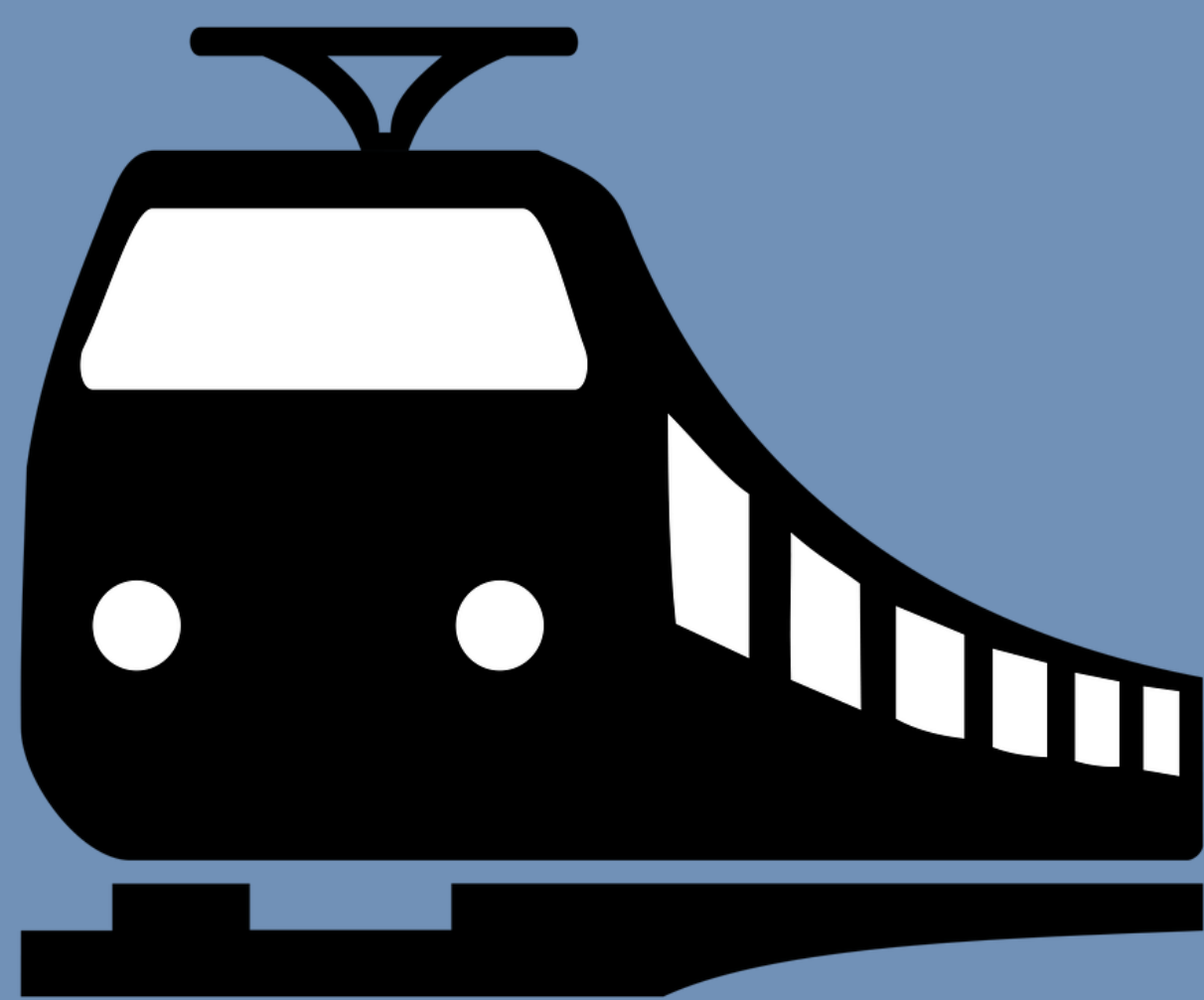


We have roughly collected 57,000 blood samples...which equates to a staggering **340 L of blood...**

OR



In 2018, we opened 41 hospital sites for the main cohort and trained another 34 for the Inception cohort. Between all coordinators we have travelled **17,550 miles...**



OR



...the equivalent of **70%** of the earth circumference!



IBD BioResource Dissemination



The IBD BioResource takes great pride in the work that it and its network undertake and is really eager to let the professional and patient communities know about its aims and progress. To spread the word and increase visibility of the IBD BioResource, the research coordinators continue to attend and present at various events and meetings throughout the UK. **2018 was a very good year for this!**



West Midlands Immunology Group, Intestinal Inflammation and Microbiota. April 2018, Birmingham. Talk



Midland Gastroenterological Society Summer Conference. May 2018, Loughborough. Exhibit



IBD Patient Involvement in Research day. May 2018, London. Exhibit



British Society of Gastroenterology Annual Meeting. June 2018, Liverpool. Poster and exhibit



Wessex Mucosal Immunology Meeting. June 2018, Southampton. Poster



Mucosal Immunology Course and Symposium. July 2018, Oxford. Exhibit



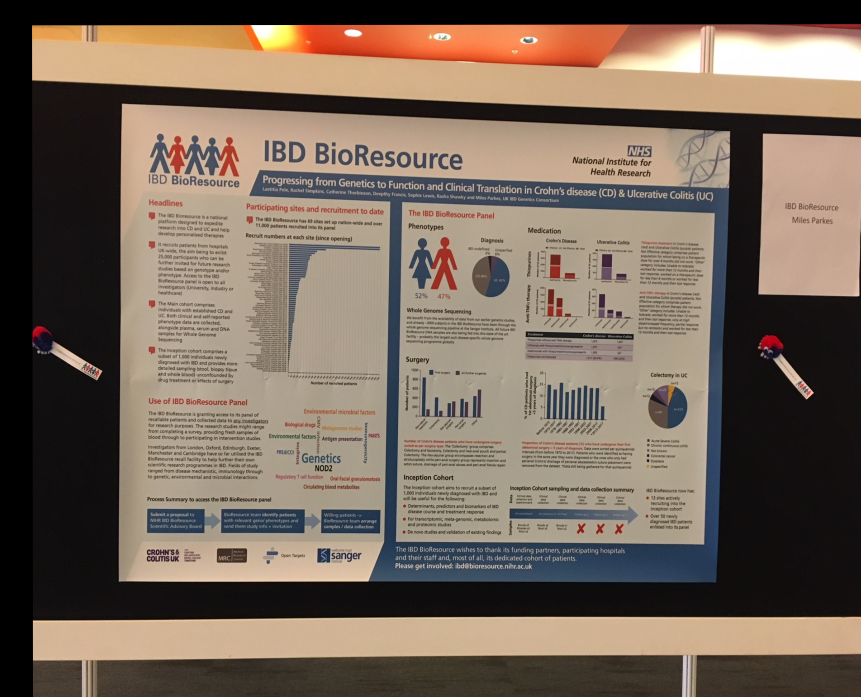
Milner Therapeutics Symposium. October 2018, Cambridge. Poster



BSG Investigator meeting. November 2018, Nottingham. Talk and Exhibit



University of Cambridge, Medicine Research day. December 2018, Cambridge. Poster





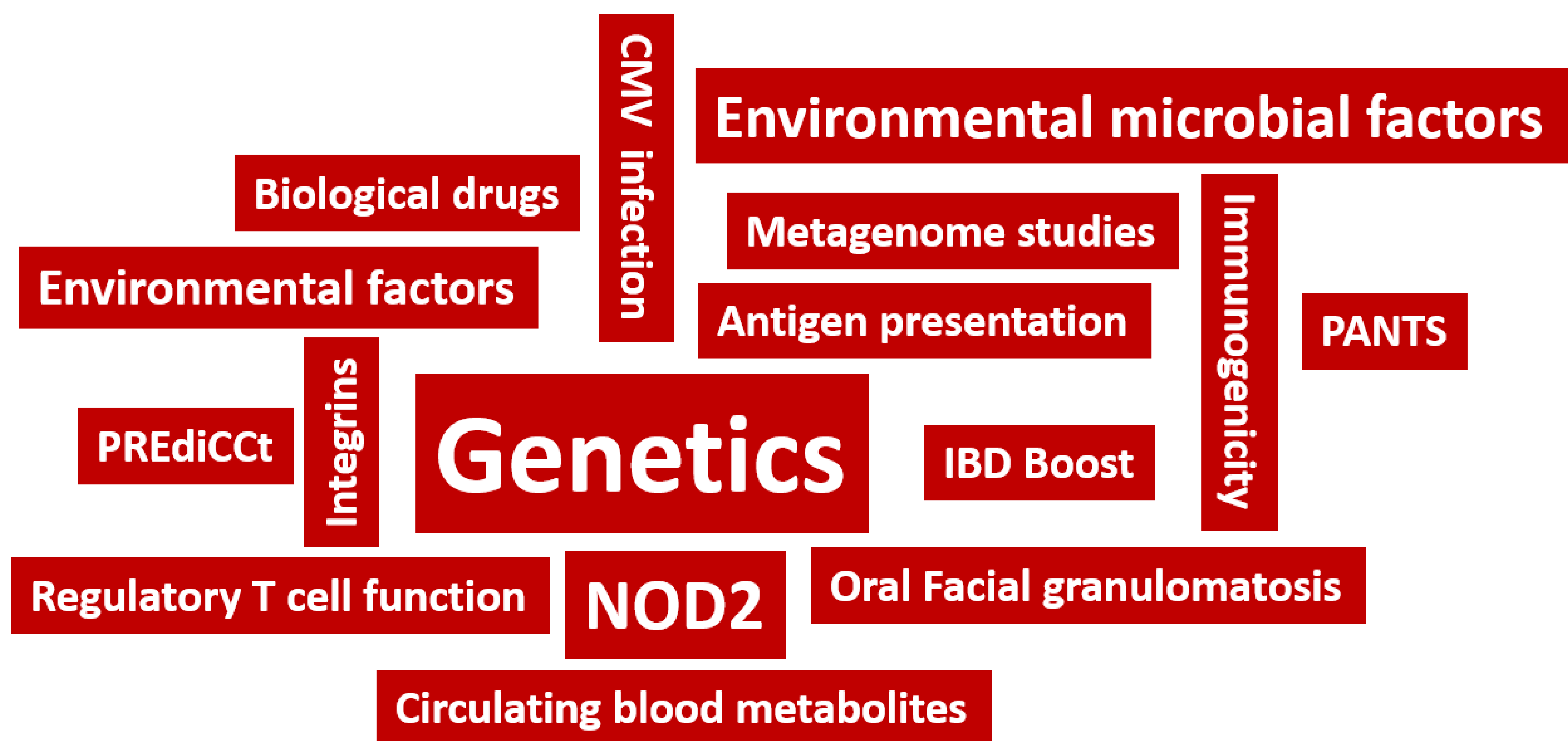
IBD BioResource Translation



The success of the IBD BioResource in facilitating important IBD research and contributing to tomorrow's treatments strongly relies on the use of its panel.

The IBD BioResource panel is open to any investigators from science or industry to undertake what is called '**Stage 2 studies**'. These may range from running surveys, accessing DNA / serum and recalling patients (possibly selected by particular genetic or IBD-related characteristics) for further samples or other studies.

To date 12 'Stage 2 studies' have applied to utilise the IBD BioResource (that's a third of all applications to the National BioResource), 11 of which are currently active. Applications have been received from renowned clinicians/academics from across the country; 4 from London, 3 from Cambridge, 2 from Oxford, 1 from Manchester, 1 from Exeter and 1 from Edinburgh. We are yet to receive an application to utilise the IBD BioResource from the Life-Sciences Industry. Field of studies ranged from disease mechanistic, immunology through to genetic, environmental and microbial interactions.



Of the 12 applications, ~40% requested access to anonymised samples and data while the remaining ~60% required involvement of participants (recall to sites / completion of online questionnaires).

THANK YOU!

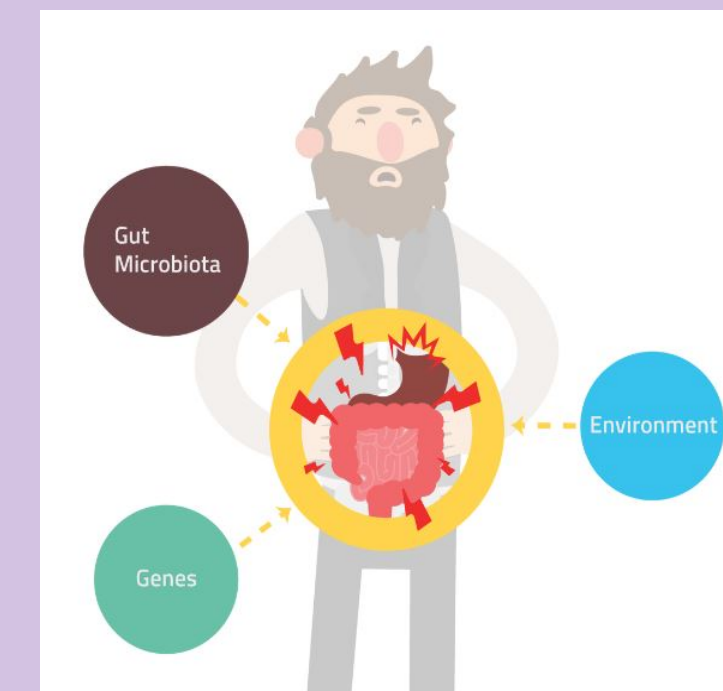


IBD BioResource Stage 2 Studies highlight



Study Highlight 1: PREdiCCt

The Prognostic Effect of Environmental Factors in Crohn's & Colitis



PREdiCCt is a study led by Dr Charlie Lees. It aims to understand how diet, lifestyle and bacteria in the gut influence flare and recovery in Crohn's disease and ulcerative colitis. To achieve this, Dr Lees and his team are looking to recruit 3,100 people in remission from Crohn's or Colitis (illness under control). They plan to follow the disease course of these individuals over 2 years whilst collecting information on the food they eat, their lifestyle and their gut bacteria.

It is hoped that a link may be found between these factors and the severity of each participant's symptom flares. For further information on the study and how to take part, please visit <https://www.predicct.co.uk/>

Study Highlight 2: IBD Boost

Living well with inflammatory bowel disease: Optimising management of symptoms of fatigue, abdominal pain and faecal urgency/ incontinence via tailored online self-management



IBD Boost is an NIHR funded study led by Professor Christine Norton. It involves the identification and recall of our IBD BioResource participants to take part in a quality of life survey. The overall purpose of this research is to find out 1) how many people with Crohn's disease and ulcerative colitis experience fatigue, pain and urgency and 2) how many want help managing these symptoms.

Volunteers will be asked to complete a survey which will take about 20 minutes and can be completed online or through a postal questionnaire. It is hoped that the results of the survey will help in testing new ways of managing these symptoms via tailored online self-management. For further information on the study and how to take part, please visit <https://www.crohnsandcolitis.org.uk/research/take-part-in-research/ibd-boost>

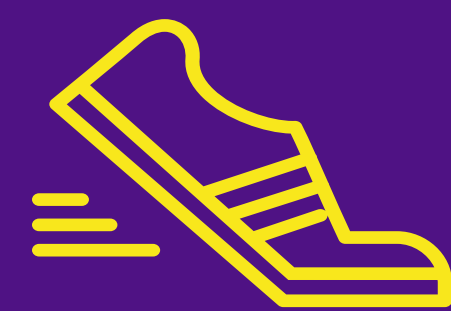
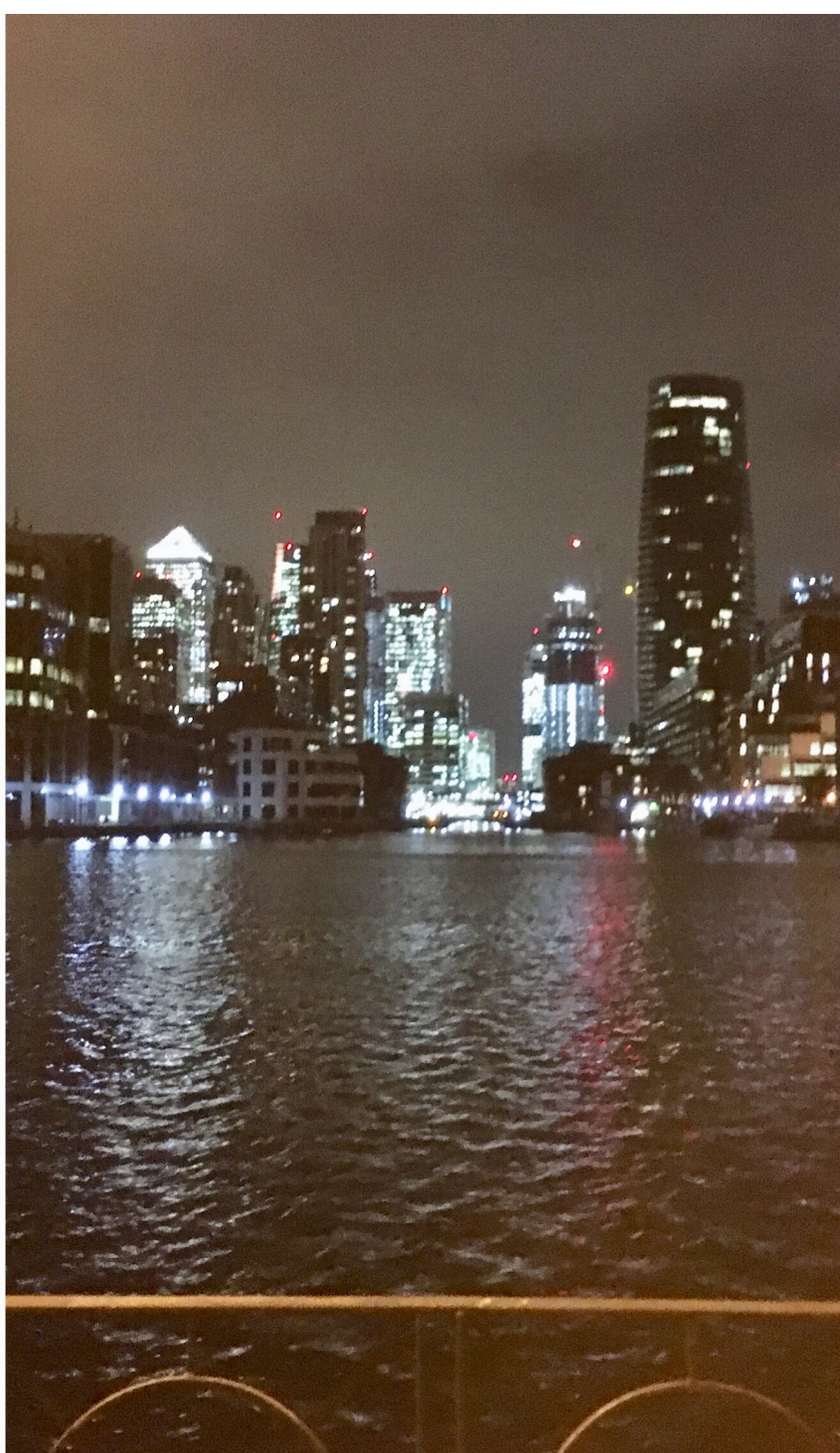


IBD BioResource Fundraising



Guts UK Charity Prudential RideLondon

On the 27th July 2018, for Gastro research, our chief investigator undertook a '100-mile cycling challenge through the closed roads of London to Surrey's testing hills before heading back to Buckingham Palace'

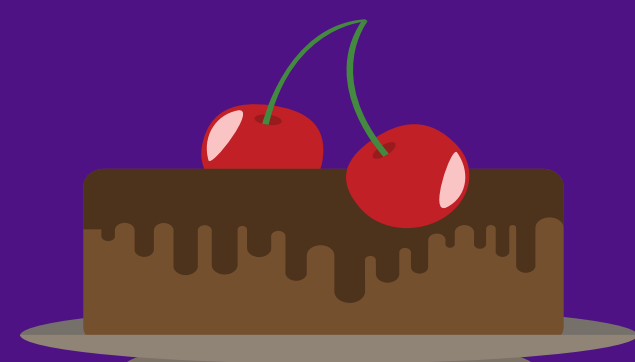
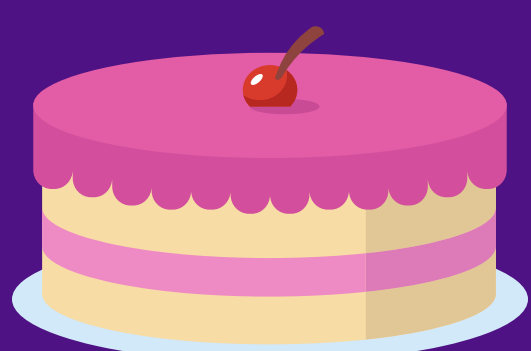


Crohn's and Colitis Run the night

On the 25th October 2018, Laetitia, one of our research coordinators 'ran a unique 10km course into the depths of a Thames tunnel and through light and sound installations across the London Docklands'

Crohn's and Colitis Awareness week

On the 08th December 2018 or Purple Friday, the IBD BioResource team proudly baked and sold all their delicious goodies at their cake bake sale!





IBD BioResource

Keeping in touch



In addition to providing regular updates on our website, we are also actively engaged on social and professional media platforms.



Check the latest on IBD BioResource

<http://www.ibdbioresource.nihr.ac.uk/>



Connect with us on Facebook

<https://www.facebook.com/IBDBioresource/>



Follow us on Twitter

https://twitter.com/IBD_BioResource



Join our professional network

<https://www.linkedin.com/in/ibd-bioresource-b011a0157/>

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