



IBD BioResource

Newsletter

January 2019



National Institute for
Health Research

Our motivation

In the UK, over 300,000 people live with Crohn's or ulcerative colitis (collectively known as inflammatory bowel disease or IBD). 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 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 patients to be recalled for future research projects based on their genetic and clinical characteristics

Our target

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



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

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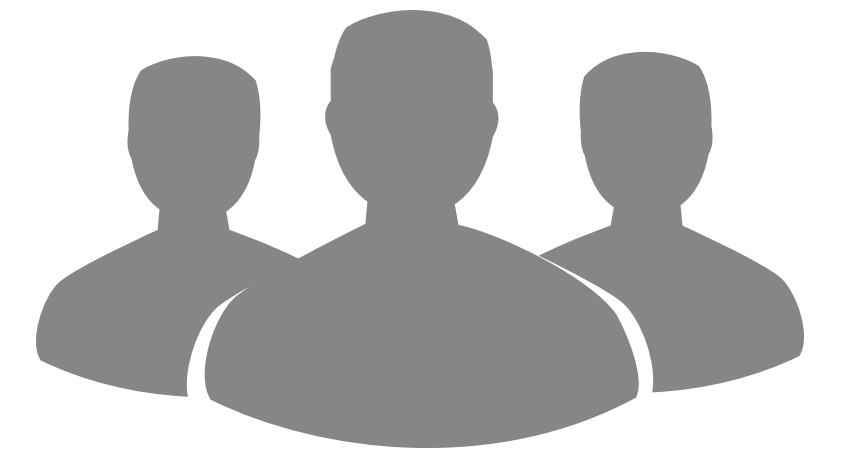
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IBD BioResource

Team news



IBD Bio Team

Chief Investigator

Dr Miles Parkes

Research coordinators

Mrs Rachel Simpkins

Mrs Cathy Thorbinson

Dr Laetitia Pele

Dr Deepthy Francis

Recruitment administrators

Miss Francesca Muldoon

Miss Edith Kaze

Mr Jonathan Mitchell

Mrs Judith Brown

Data management

Mrs Rasha Shawky

Changes to the admin team

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.

We also give a fond welcome to Mr Jonathan Mitchell and Mrs Judith Brown who joined the administrator team at the beginning of 2019.



CROHN'S & COLITIS UK

FUNDRAISING



Crohn's and Colitis Awareness week

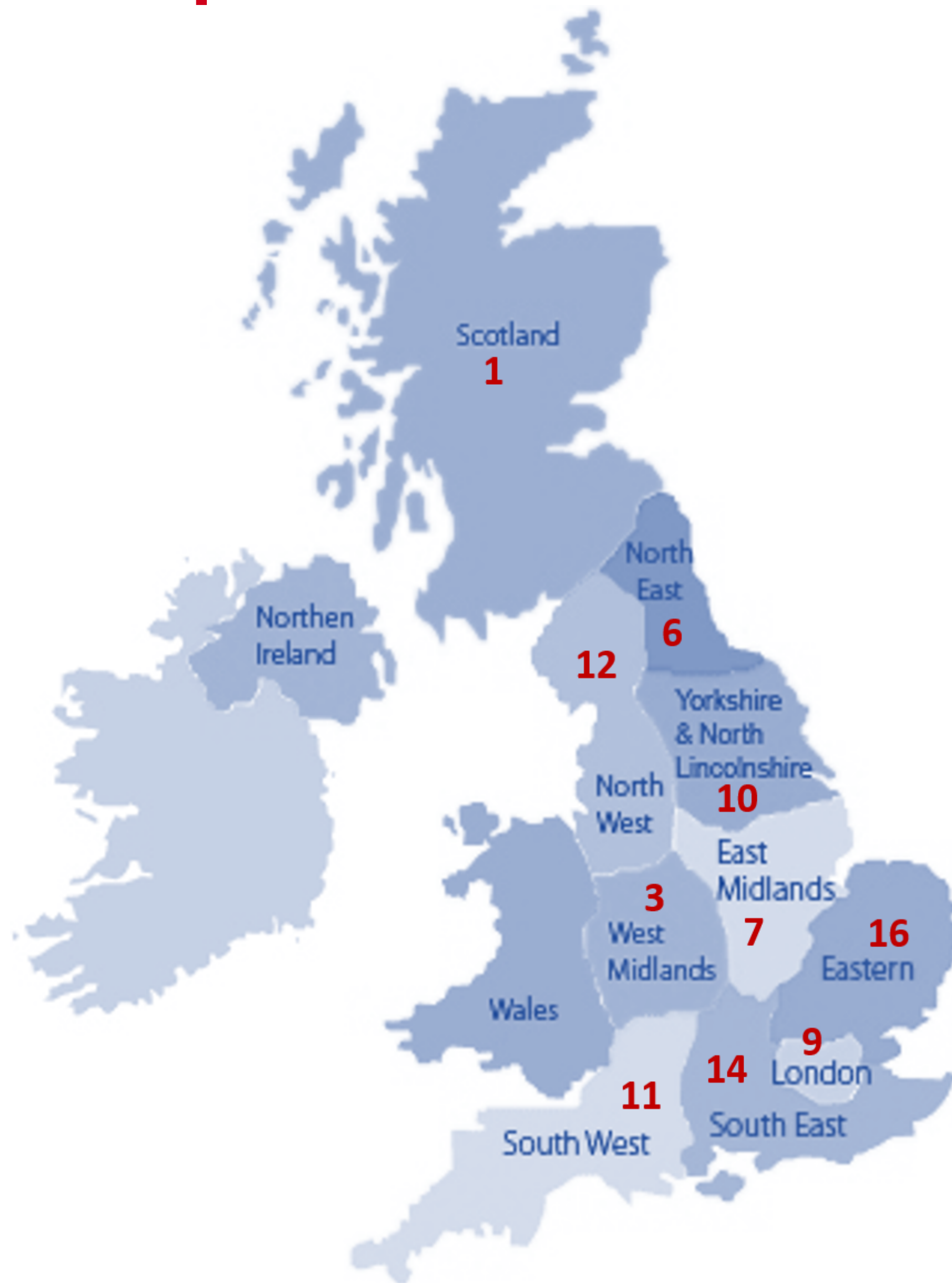
On purple Friday, the IBD BioResource team organised a cake bake sale and helped raise money for Crohn's and Colitis UK.



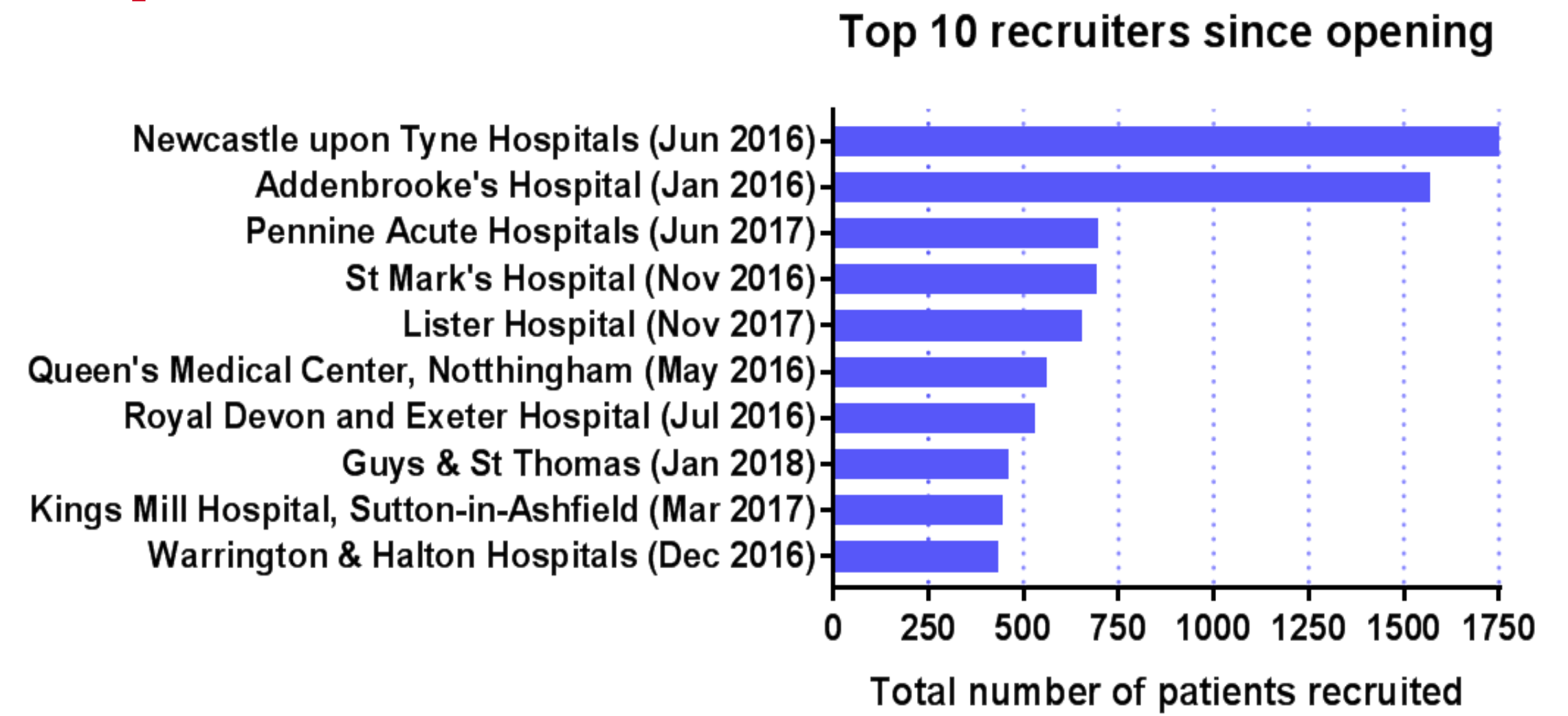
IBD BioResource Main Cohort



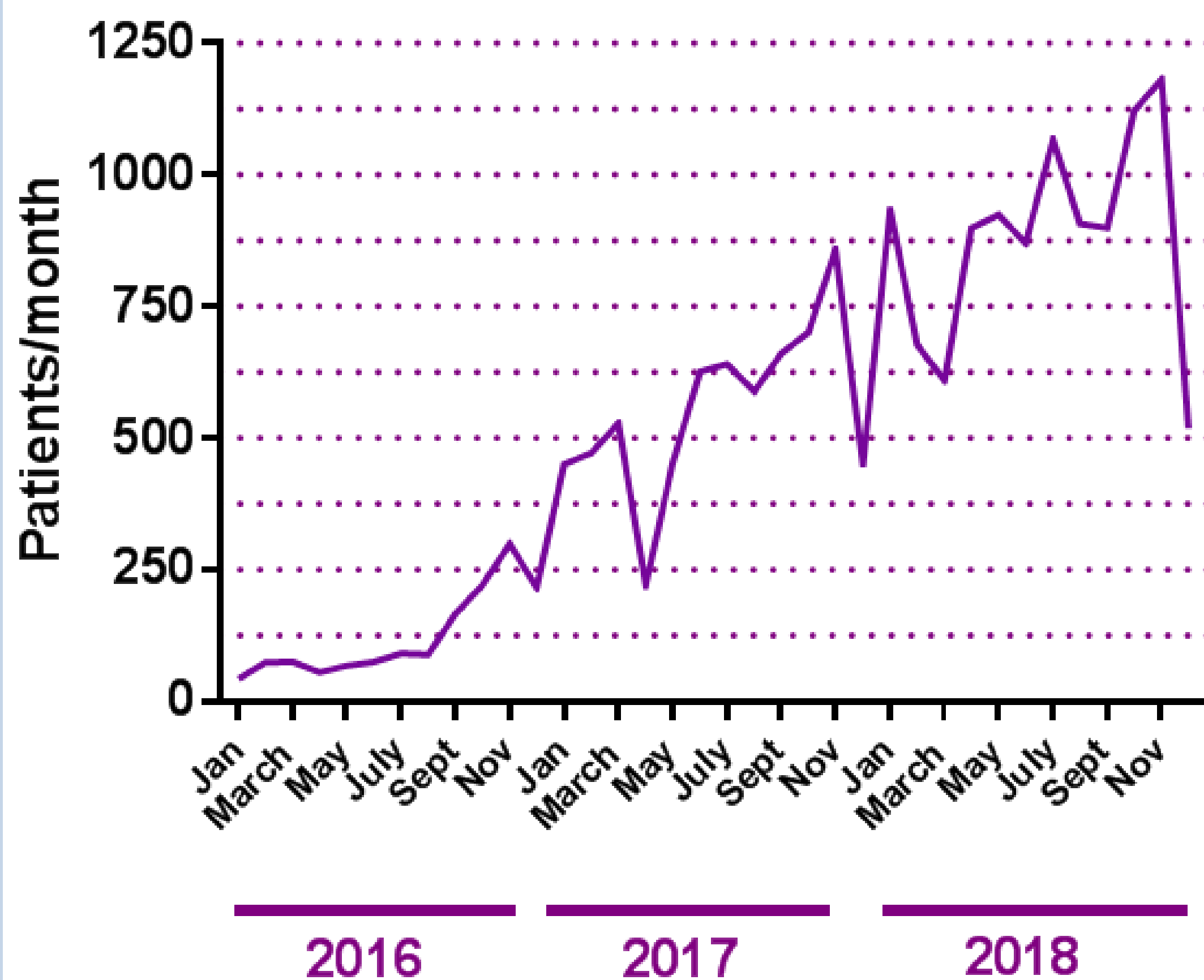
Site map



Top 10 recruiters



Recruitment rate



Summary

Since the last newsletter, 12 new hospital sites have joined the IBD BioResource. This takes the number of sites open and recruiting to a grand total of 89 so far! A further confirmed 14 sites will be set up during the course of 2019.

We are also very excited to have set up our first site in Scotland, which is being led by Dr Charles Lees and his team at the Western General Hospital, Edinburgh. Hopefully more to follow!

Volunteer recruitment is still going strong and we now have over 19,000 patients enrolled into our IBD BioResource panel.

Let's keep up the good work!!!





IBD BioResource Inception



Inception

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. Samples from this cohort will be particularly valuable for a variety of different experimental designs. 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. Therefore if you have not yet been trained in the Inception cohort expect an email from Rachel Simpkins to arrange a time to do this, or do feel free to take the initiative if it is something that you would be keen to start! It is important to highlight the following key points about the Inception cohort -



We only require a minimum recruitment of 5-10 patients per year at each site (more would obviously be very welcome!)



It is a key part of the protocol for the study and as such has already been approved by your R & D office for delivery at your site, therefore it does not require any further approvals or agreements

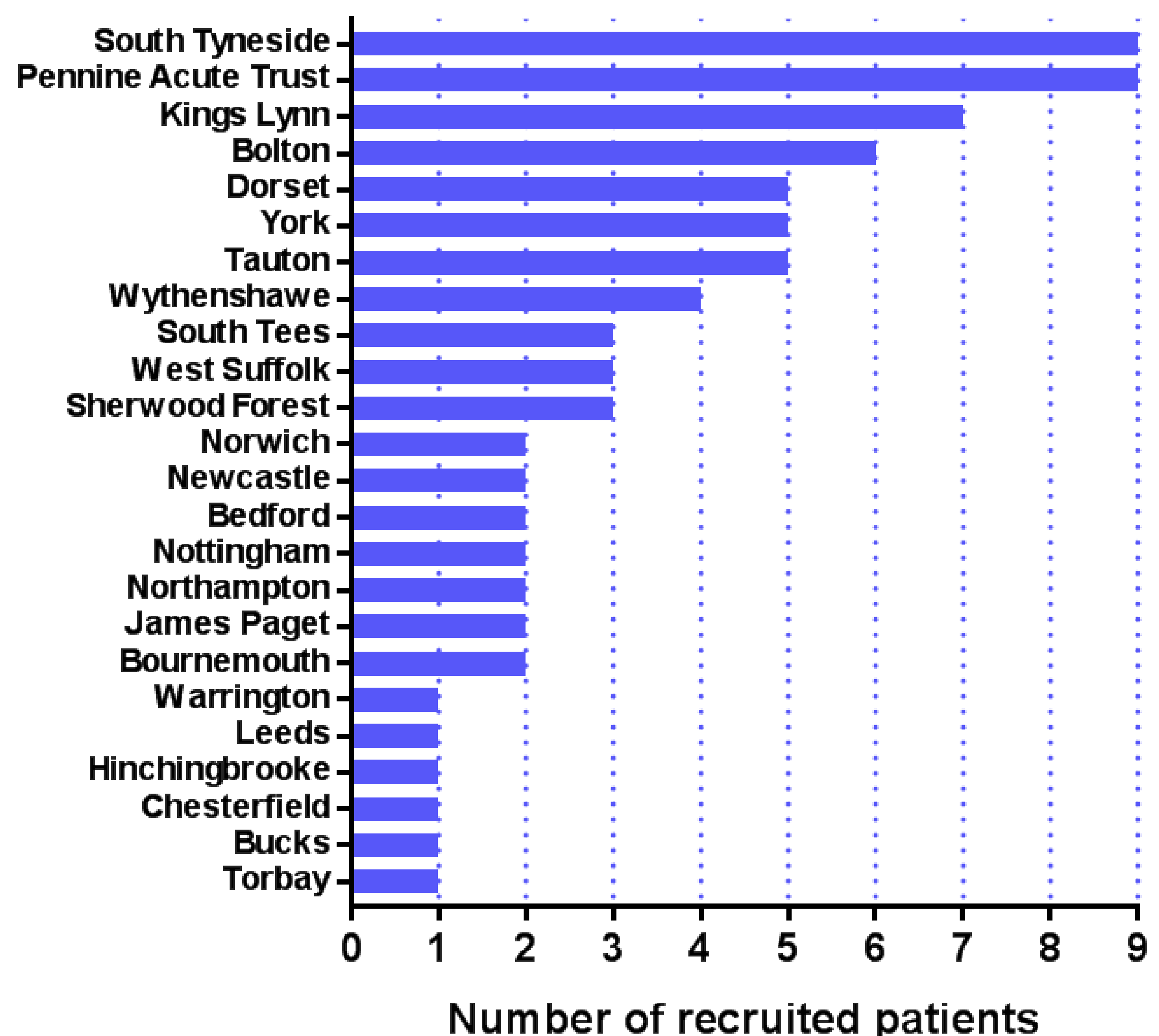


It is possible that recruitment of patients and collection of their samples at your site may require different arrangements and the involvement of different staff to the recruitment for the main cohort. Therefore it may be a good idea to start looking at that in advance so that you are ready to go once the training is complete

Site map



Recruitment per Site





Data curation and data quality

With the number of sites currently recruiting for IBD BioResource and over 19,000 patients enrolled across 80+ sites, a wealth of clinical and phenotypic data are being collected. IBD BioResource has now implemented a data curation review and data clean-up process to guarantee that data quality is met. Such course of action is paramount and will ensure that downstream research studies have access to a robust IBD BioResource panel.



IBD diagnosis

Date of diagnosis

Smoking status at diagnosis

Email address

CROHN'S DISEASE

Sites involved
Behaviour
Perianal involvement
Surgery

ULCERATIVE COLITIS / IBDU

Max. macroscopic extent
Colectomy/Indications

Implemented changes

In order to standardise sample processing and storage across all NIHR BioResources, including IBD BioResource, all blood samples are now collected in vacutainers and sent to the National Biorepository Centre (NBC) in Milton Keynes. Inception samples (biopsies, additional serum and PAX tubes) are now going to Edinburgh. See summary table below:



Cohort	Contents of bag	Previous address	NEW ADDRESS
Main	2 x EDTA and 1 x serum blood tubes	LGC, Hoddesdon	NBC, Milton Keynes
Inception	<u>Baseline 1</u> - 2 x EDTA and 1 x serum blood tubes	LGC, Hoddesdon	NBC, Milton Keynes
Inception	<u>Baseline stool</u> – 1 x universal tube with RNA later and 1 x OMNIGENE Gut tube	Sanger, Hinxton	Edinburgh
Inception	<u>Baseline 2</u> – 1 x serum and 1 x PAX gene RNA tubes	Sanger, Hinxton	Edinburgh*
Inception	Spare biopsy jiffy bag	Sanger, Hinxton	Edinburgh*
Inception	<u>Follow up 1</u> – 1 x serum and 1 x PAX gene RNA tubes	Sanger, Hinxton	Edinburgh*
Inception	<u>Follow up 2</u> - 1 x serum tube	Sanger, Hinxton	Edinburgh*

* From 28th January 2019



IBD BioResource

NEW

Changes to come ...

During the course of 2019, we will be providing sites with brand new barcode ID labels with a view, once again, to standardise processes across all NIHR BioResources. In place of sending sample manifests, sites will instead complete a sample linkage form and add to the jiffy bags alongside samples.

Old labels



New labels



NIHR BioResource for Translational Research
IBD BioResource

NHS
National Institute for
Health Research

Sample Linkage Form

Collection Event

Project RTB-IBD

Hospital name or
three letter code _____

Collected by (name) _____

Date _____

Time _____

Participant Linkage
do not include any other details

Item ID attach barcode here Age _____ Gender _____

Tube type Tick if collected

Vacutainer EDTA 4.0 ml ☐

Vacutainer EDTA 4.0 ml ☐

Vacutainer Serum 6.0 ml ☐

Please complete all sections.

NIHRBR-slf-UK-02-1010-10-22

Substantial amendment 4



IBD BioResource is continually reviewing their patient facing documents as well as the clinical research forms to make sure that capturing and recording of information is done in an efficient and easy manner. We are therefore currently in the process of making changes to various documents, including a simplification of the protocol, all of which should hopefully be ready for implementation in your teams by Easter time. The research coordinators will be updating you about the progress accordingly.



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.



**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**

**We want the IBD BioResource to be used by
researchers and to drive advances in knowledge ASAP**



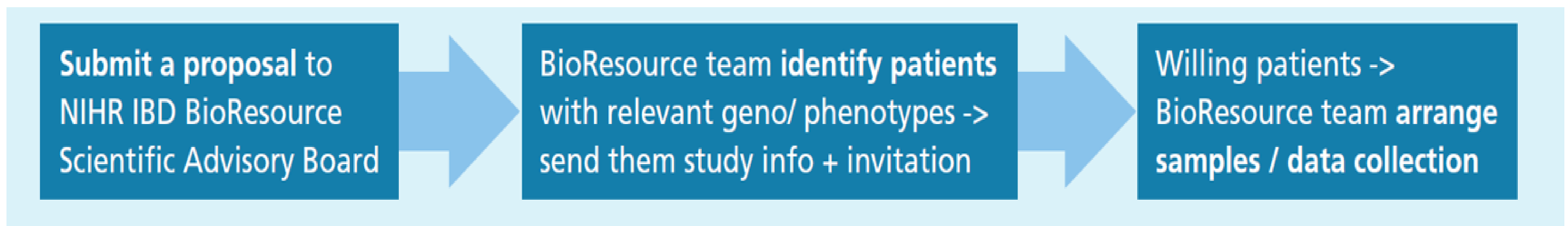
IBD BioResource Stage 2 studies



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 – Range of possible studies include running surveys, accessing DNA / serum and recalling of pheno / geno-type-selected patients for further samples or study.

Stage 2 study submission process



Stage 2 Study Highlight: 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.



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/>

Contact details

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