



IBD BioResource

Newsletter

August 2018

NHS
National Institute for
Health Research

Our motive

In the UK, over 250,000 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.



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IBD BioResource

Team news



With the ever expanding number of hospital sites taking part in the IBD BioResource study, we have welcomed two additions to our IBD BioResource coordinator team (Laetitia Pele and Deepthy Francis) and two in our volunteer recruitment administrator team (Edith Kaze and Hannah Cheesman). We also said goodbye to Sophie Lewis who went on maternity leave in January.



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

Mrs Hannah Cheesman

Mr Jonathan Mitchell

Data management

Mrs Rasha Shawky



From left to right: Deepthy, Laetitia, Miles, Cathy, Rachel, Rasha, Francesca and Edith.

Newest members of the Research Coordinator Team

Dr Laetitia Pele joined the IBD BioResource team in January 2018. Prior to her appointment, she spent the last 12 years as an investigator scientist researching the effect 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 communications.

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 main interest lies in scientific research that benefits the public and help to improve the quality of life of patients in innovative ways.

Newest members of the Volunteer Recruitment Administrator Team

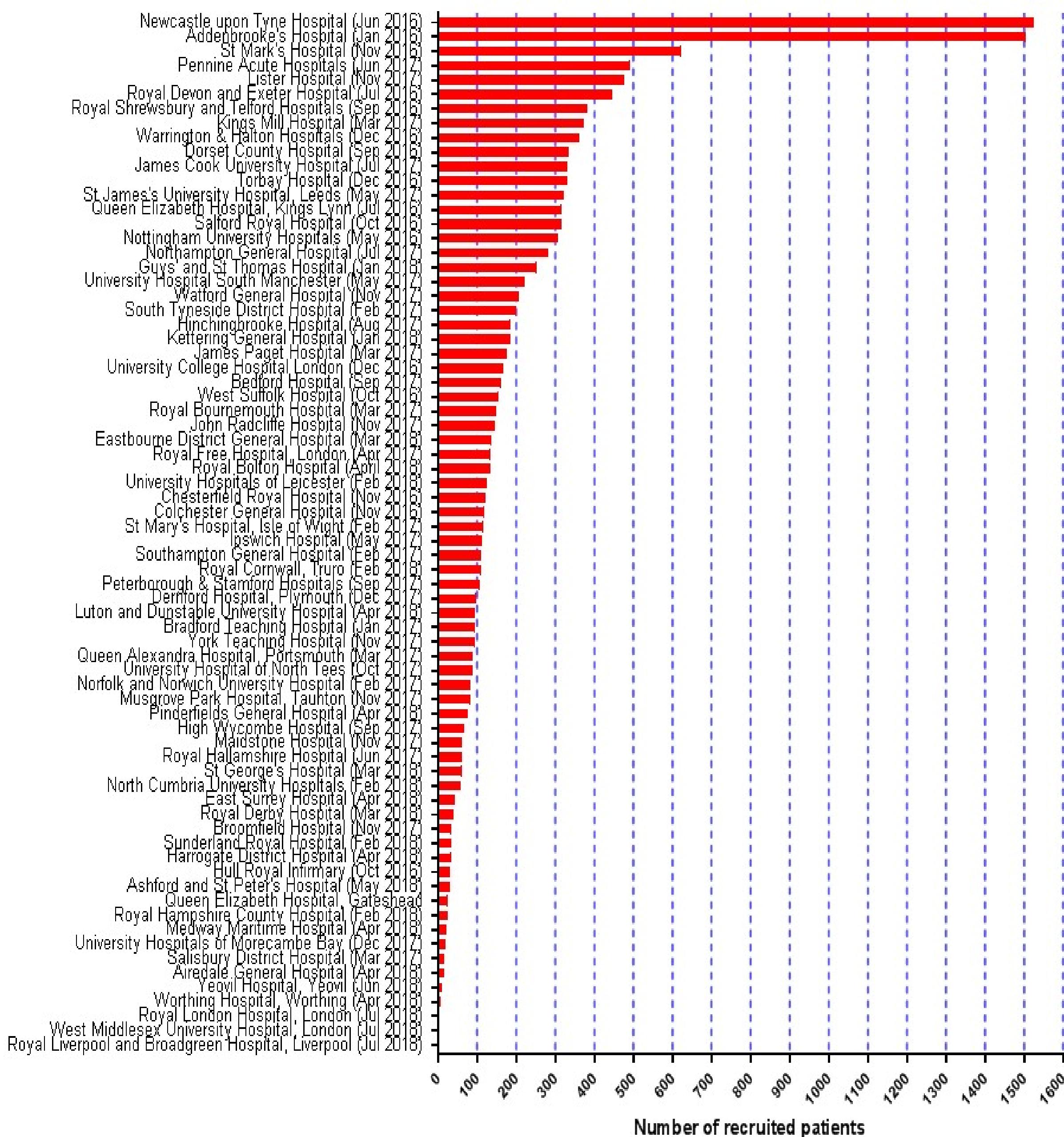
Miss Edith Kaze joined the IBD BioResource team in January 2018. Prior to her appointment, she was working as an Adviser for the Modern Slavery Helpline. In addition to this, Edith has worked in a range of administrative as well as care giving roles in the NHS for a number of years. She has also worked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

Mrs Hannah Cheesman joined the IBD BioResource team in February 2018. Prior to working with the IBD BioResource she worked within the Mental Health Sector for Children and Young people.



IBD BioResource

Progress so far



Main Cohort

Since the beginning of 2018, 17 new hospital sites have joined the IBD BioResource and a further 21 will be set up by the end of the year. At the end of July, this takes the number of sites open and recruiting to a grand total of 77!

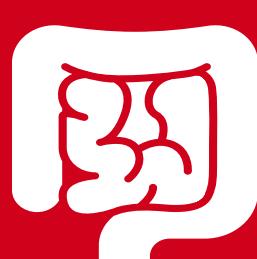
Volunteer recruitment is going well too (graphical breakdown of recruitment per sites is shown on the left) and we now have over 14,000 patients enrolled into our IBD BioResource panel, 5,000 of whom have had their genome fully sequenced. So thank you everyone for the stellar job so far – but let's keep it up! We want to get the next 11,000 recruited as soon as possible...

Thanks to the growing panel of IBD patients, we are now focusing our efforts on publicising the IBD BioResource. We want to make it known and accessible to any investigators around the UK with an IBD interest so that outstanding research is made possible.

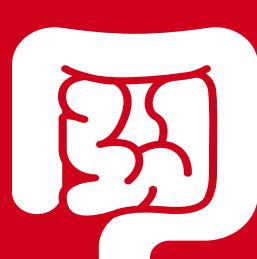
Inception

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 19 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



IBD BioResource

NEW

Health and lifestyle questionnaire

We have a brand new format of the Patient Health and Lifestyle Questionnaire for patients to complete. This new questionnaire is much more clear, machine readable and user friendly.

The machine readable ability of the questionnaire will help us to export the populated data from paper questionnaires straight into our database in a fast, accurate and efficient manner and by-passing the need to input data manually.

The system has been robustly tested and we are now satisfied and confident with it. We will be implementing this questionnaire to all sites very soon, so watch this space! Questionnaires will be provided in a protected version with your Trust logo so that printing does not interfere with the formatting and machine readability. Patients providing their email address will still have the option to complete the online version— which saves paper and postage, and is still our preferred option where possible!

This form will be scanned. Please answer ALL questions by using BLOCK CAPITALS in the spaces provided or crossing the relevant boxes. e.g. A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

Patient Health and Lifestyle Questionnaire
Version 4.0 19/06/2018

National Institute for Health Research

OFFICE USE ONLY
Attach Barcode Label Here

1. DEMOGRAPHICS

a. Your Height
(please specify units) . Metres & cm Or Feet & Inches

b. Your Weight
(only one measurement type is required) kg Or st lbs

c. Are you right or left handed? Right Left Both / Ambidextrous

d. Your date of birth / /

e. Your gender Male Female

f. What is your employment status?
 Full time Part time Retired Student Unemployed
please specify what your job is / was:

g. Do you have a specific diet?
 No Vegetarian Vegan Pescatarian
 Other - please specify

2. IBD SPECIFIC HEALTH QUESTIONS

a. What type of inflammatory bowel disease are you affected by?
 Crohn's disease
 Ulcerative colitis
 IBD type unspecified
 Unsure
 Not affected

b. Approximate month and year of diagnosis /

c. Approximate month and year of first symptoms /

d. Have you ever been admitted to hospital for treatment of Crohn's / Ulcerative Colitis?
 Yes No Don't know

e. Have you had your appendix out?
 Yes No Don't know
If yes, what year did you have your appendix out?

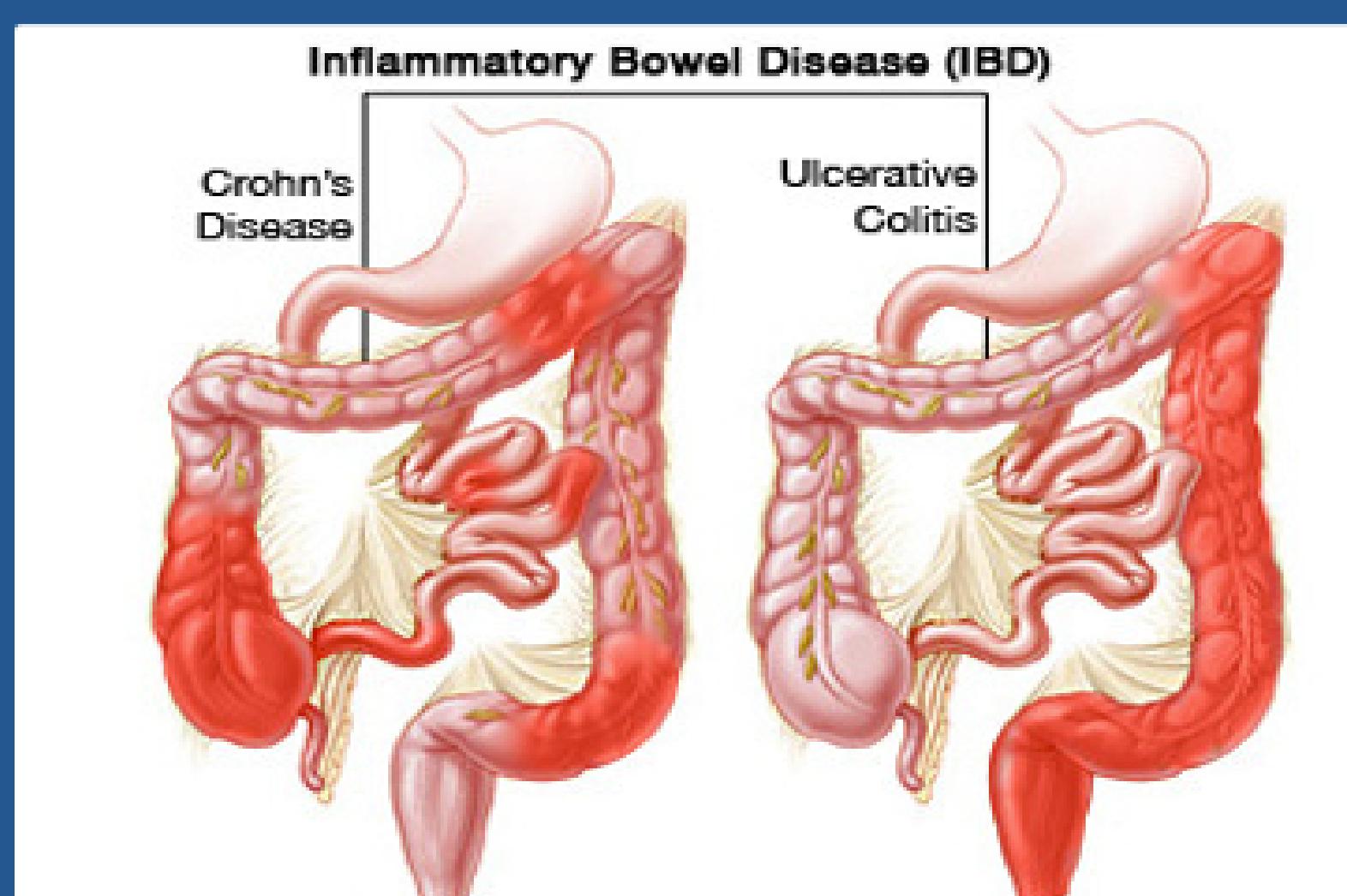
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IBD phenotype

To enable smooth data curation and keeping proper records of phenotypic data, we have made the inclusion criteria clearer. See list below.

CROHN'S DISEASE

- Crohn's Colitis
- Crohn's pancolitis
- Ileal Crohn's
- Terminal Ileal Crohn's
- Ileal-caecal Crohn's
- Crohn's Ileitis
- Crohn's jejunio-ileitis
- Oral Crohn's
- Oral Facial Granulomatosis



ULCERATIVE COLITIS

- Ulcerative Colitis
- Proctocolitis
- Proctitis
- Pancolitis
- Total Colitis
- Distal Colitis
- Left-sided Colitis
- Proctosigmoiditis

IBDU
Indeterminate IBD
Unspecified IBD



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 have attended and presented at various events and meetings in the fields of Gastroenterology, Immunology and Patient Involvement in Research throughout the UK. We want the IBD Bioresource to be used by researchers and to drive advances in knowledge ASAP



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



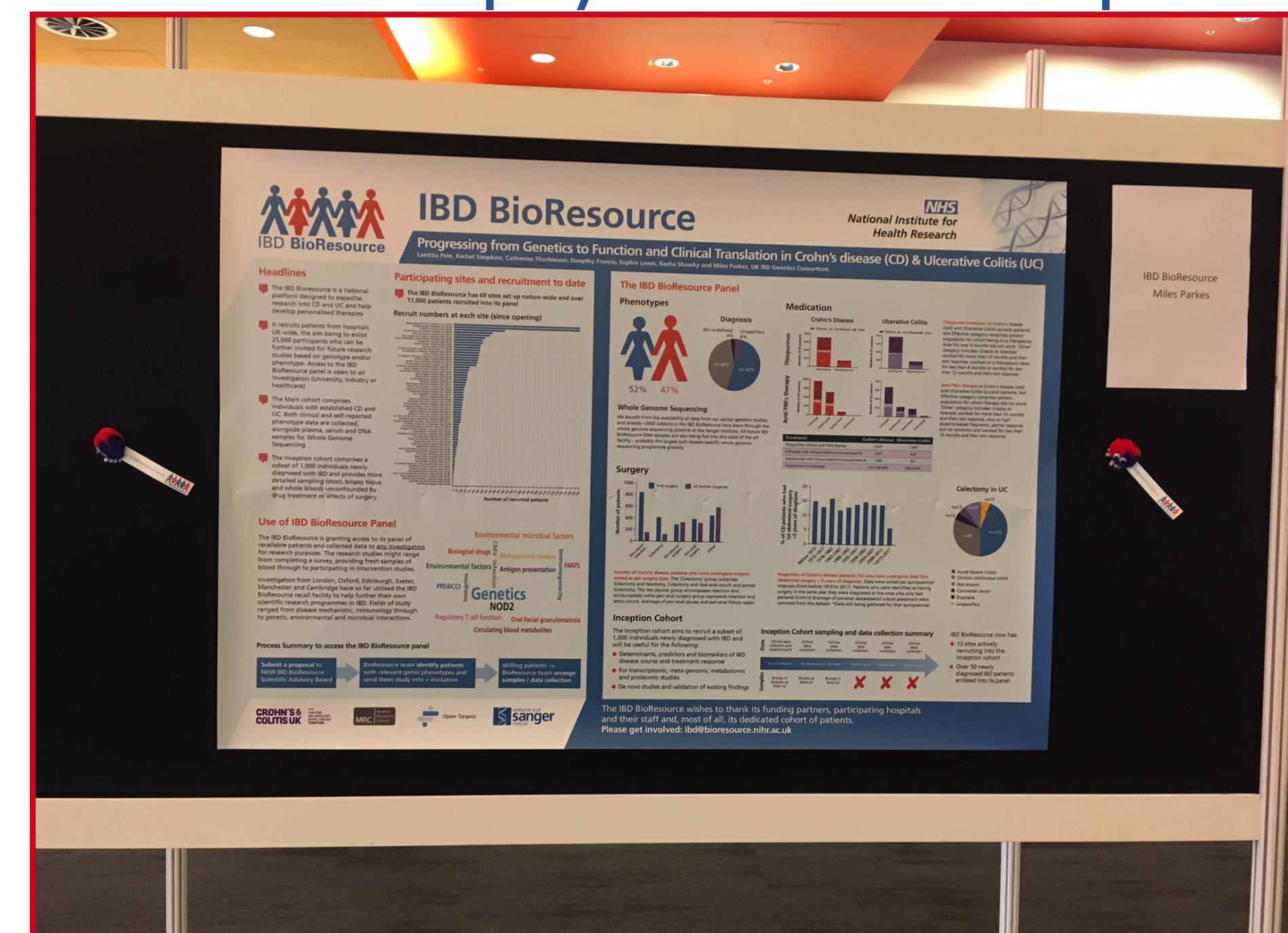
Wessex Mucosal Immunology Meeting. June 2018, Southampton. Poster



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



Laetitia and Deepthy at the BSG in Liverpool.



IBD BioResource poster at the BSG in Liverpool.



Laetitia and Rachel at the MICS in Oxford.

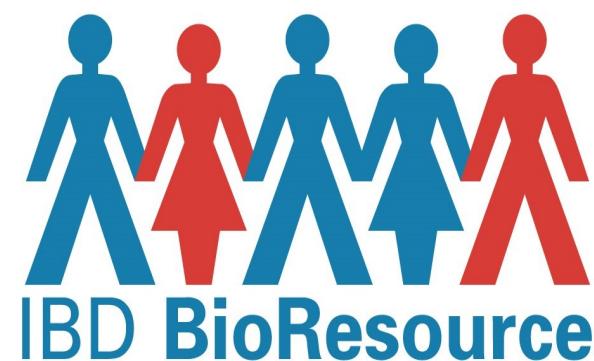


IBD BioResource

Keeping in touch

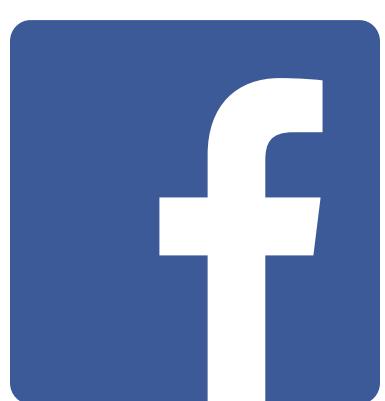


In addition to providing regular updates on our website, we are also actively engaged on social and professional media platforms.



Check the latest on IBD BioResource

<http://www.ibdbioresouce.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-bioresouce-b011a0157/>

Contact details

To keep site contact details up to date, please fill in the form attached and send back to:
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