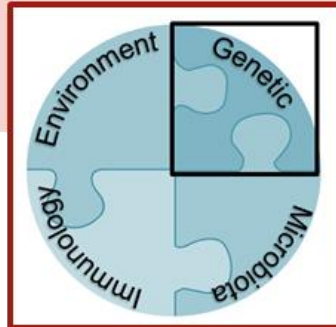


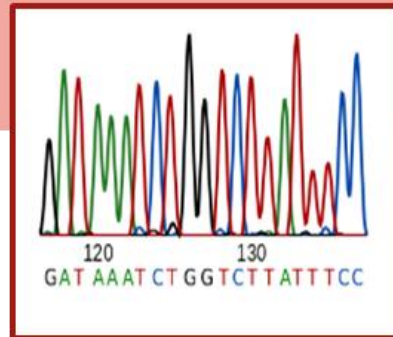
# - The UK Inflammatory Bowel Disease BioResource - Progressing from Genetics to Function and Clinical Translation in Crohn's Disease & Ulcerative Colitis in adults, young people and children”



Inflammatory  
Bowel Disease



IBD BioResource  
50,000 Recallable  
patients



Panel open to any  
investigators



Translation



# IBD BioResource goals

## Main cohort:

- 50,000 IBD patients
- Clinical data
- Health & lifestyle data
- Blood samples banked
- Genome wide analyses

## Inception cohort:

- 1,000 patients newly diagnosed with IBD
- Longitudinal clinical data or PROM
- H&L information
- Stool + biopsies
- Genome wide analyses

## Banked clinical samples

Main and Inception cohort

DNA  
Serum  
Plasma

Inception cohort only

Stool  
Biopsies  
Paxgene

## Clinical data

### CROHN'S DISEASE

- Macroscopic extent
- Perianal involvement
- Behaviour
- Surgery
- Stoma



- IBD diagnosis
- Date of diagnosis
- Smoking status at diagnosis
- Email address
- Medication and treatment response

### ULCERATIVE COLITIS/IBDU

- Max. macroscopic extent
- Surgical colectomy
- Ileo-anal pouch



## Health and lifestyle data

Demographics, IBD specific health, general health conditions (e.g. allergies, diabetes, cancer etc), lifestyle, family history of IBD, coronary heart disease and cancer.

**Intention:** platform for UK IBD research - by any investigator

# Driving IBD Research: What can we support ?

We want IBD BioResource to be used!

IBD BioResource panel can be accessed by any investigators - supports a range of studies:

- access to data only – *Data Access Application (DAA)*
- data + banked samples – *Stage 2 Study*
- recall of selected participants => samples, surveys, experimental medicine etc – *Stage 2 Study (ethics required)*

If you or your colleagues have a study in mind requiring the selection of patients according to a specific phenotype and / or genotype, or you want to get access to some data and samples ... we can help!

[ibd@bioresource.nihr.ac.uk](mailto:ibd@bioresource.nihr.ac.uk)

0800 090 2233



**GET IN TOUCH!**



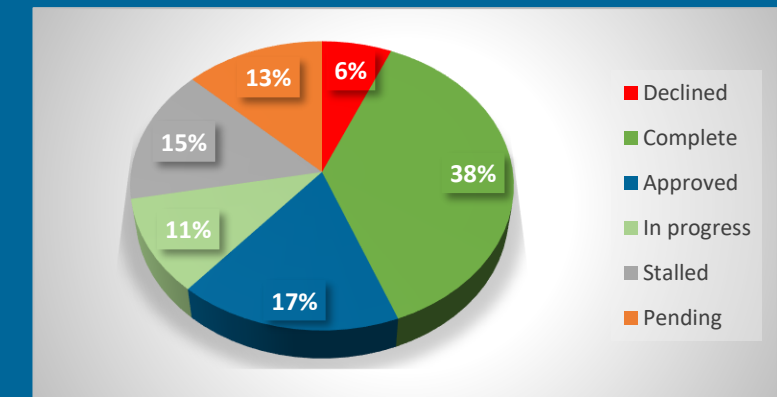
To date 93 applications received to access the IBD BioResource panel.

⇒ 43 DAA and 50 Stage 2 studies

## Number of applications across the years



## Applications Status



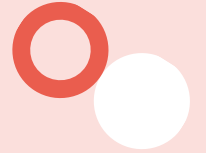
# Taking Part in the IBD BioResource – it's easy!

- Simple study to run - on NIHR portfolio (No. 20664)
- To take part please email [ibd@bioresource.nihr.ac.uk](mailto:ibd@bioresource.nihr.ac.uk)
- *Registered to the NIHR associate PI Scheme*
- >100 hospitals => 45,000 IBD patients recruited
  - >1,000 newly diagnosed
  - >200 paediatric patients (9 sites open)
- ~33,000 recruited pre-pandemic => need 'Data Refresh' re *treatment outcomes*
  - >4 yrs more data eg on anti-TNF LoR + new IBD drugs  
=> Understand determinants of response / non-response / loss of response

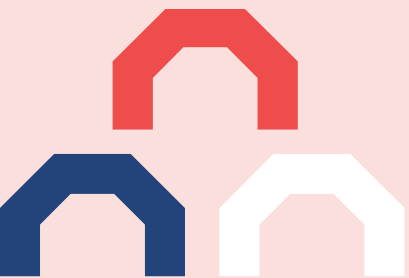
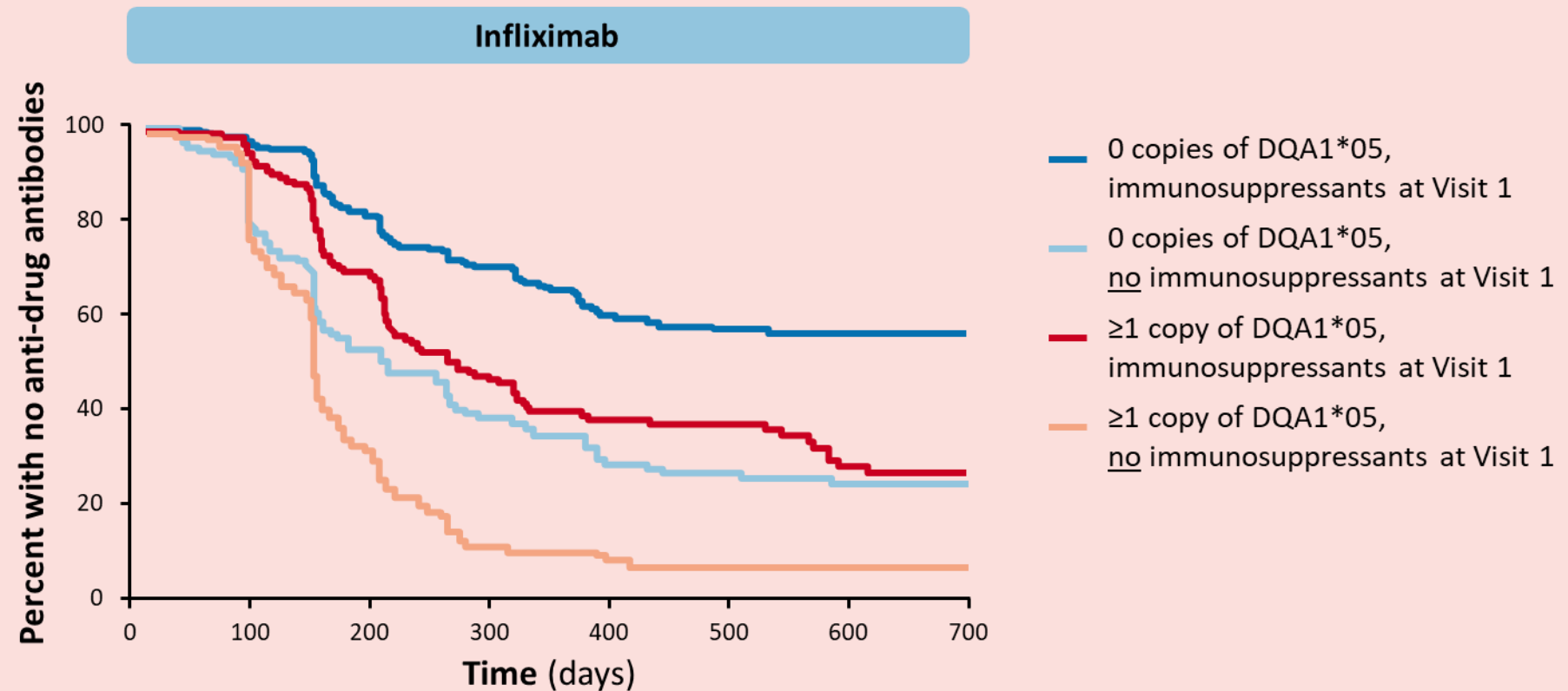
Sazanovs et al Gastro 2020  
Kapizioni et al JCC 2023



# Does DQA1\*05 predict loss of response and treatment failure?



Evolution of ADA by genotype and immunomodulator status in the PANTS study



Call to arms – SpRs, fellows, IBD nurses, research nurses, consultants!

We are doing online (REDCap) ‘Refresh’ for 33,000 participants recruited <1<sup>st</sup> March 2020

**Payment**

- Core IBD phenotype + ‘Advanced therapy’ response –
  - 10-20 minutes – (most 10 mins!) £20

Or

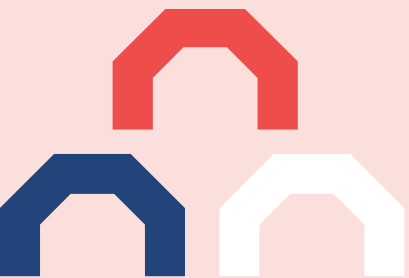
- Core IBD phenotype only (no advanced therapy used)
  - 5-10 minutes - £10

**+ banner authorship for data on >100 pts**

**Target completion date 30-08-24**



Sites who have started the Data Refresh



Airedale General Hospital	180
Ashford Hospital	274
The Royal London Hospital	448
Bedford General Hospital	316
Queen's Hospital	135
Bradford Royal Infirmary	135
Basildon University Hospital	462
Wycombe Hospital	147
Addenbrooke's Hospital	2014

Luton and Dunstable University Hospital	169
Macclesfield District General Hospital	108
Broomfield Hospital	139
Milton Keynes University Hospital	126
Medway Maritime Hospital	86
Manchester Royal Infirmary	1
The Maidstone Hospital	105
Cumberland Infirmary	96
North Devon District Hospital	171

Scarborough Hospital	110
Whiston Hospital	253
St James's University Hospital	473
St Marks & Ealing Hospital	896
James Cook University Hospital	589
Salford Royal	673
St George's Hospital	347
South Tyneside District Hospital	403
Stepping Hill Hospital	5

University Hosp	
University Hospital of	
& Darlington Men	
Colchester Gene	
Chesterfield Ro	
Dorset Count	
Darent Valley	
Western Gene	
QEQM & William H	
Royal Blackbur	
Lister Ho	
Gateshead	
Guy's Ho	
Basingstoke, North	
Royal Hampshire C	
Harrogate Distr	
Hinchingbrook	
Princess Alexan	
Hull Royal It	

>10,000 notes already refreshed – THANKS!!

	85
	624
	160
	471
	193
	130
	4
	387
	81
	219
	456
	242
	512
	13
	84
	556
	178
	317

St Mary's Hospital (HQ)	33
St Mary's Hospital, IOW	131
James Paget University Hospital	305
King's College Hospital	291
Kettering General Hospital	623
Queen Elizabeth Hospital, King's Lynn	466

Royal United Hospital	277
New Cross Hospital	817
Salisbury	17
East Surrey Hospital	183
Royal Shrewsbury Hospital	586
Singleton Hospital	20

St Richard's & Worthing Hospital	476
Royal Albert Edward Infirmary	112
Yeovil District Hospital	117
York Hospital	247

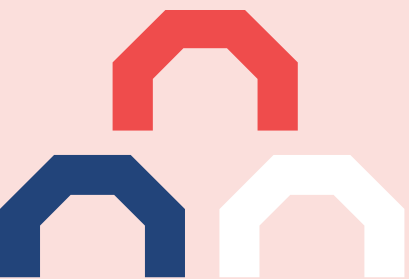
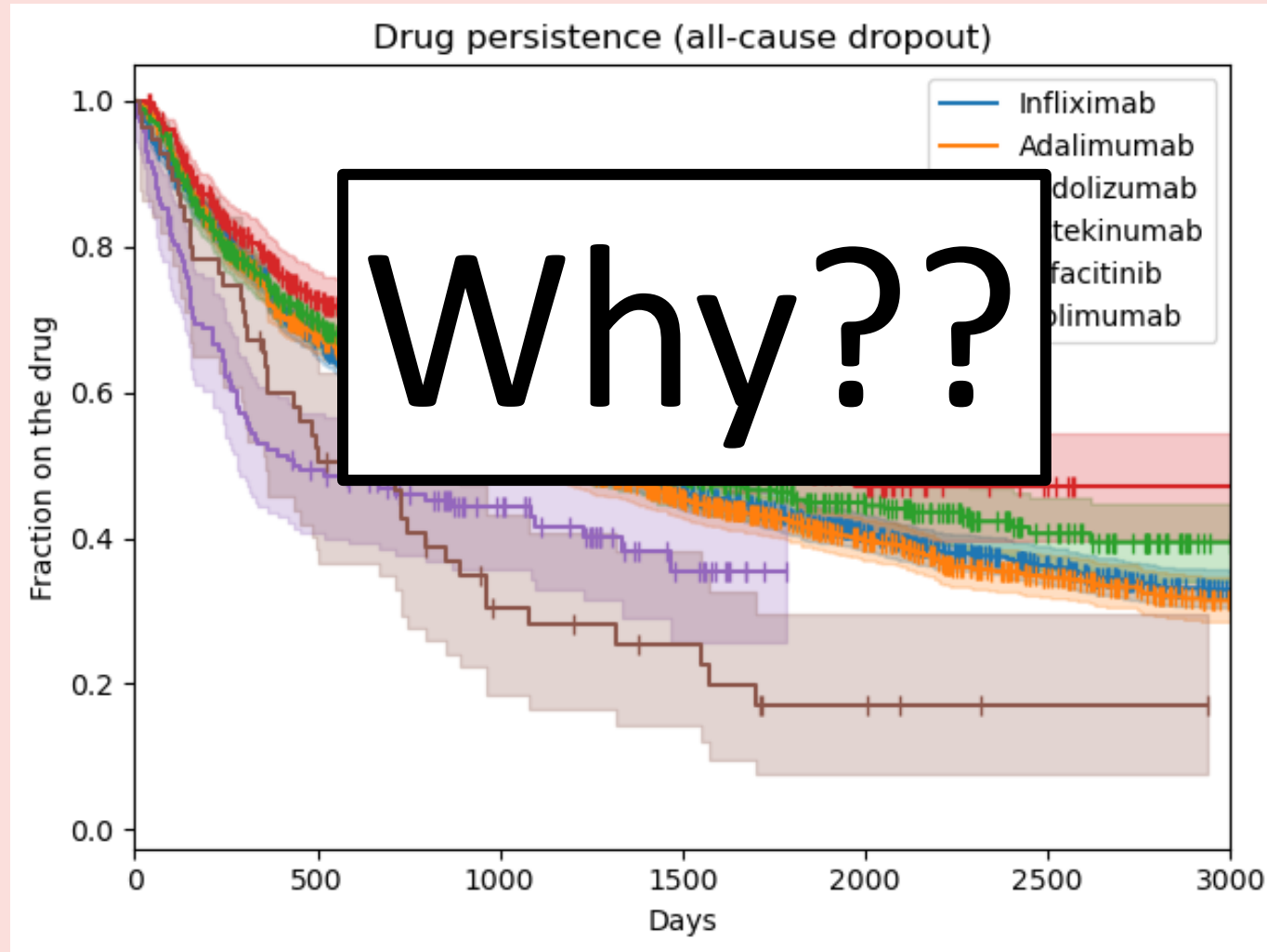
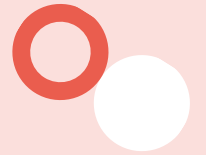
Data refresh complete

Data refresh underway

Data refresh initiated

Data refresh not started or site to contact

## Persistence of Advanced IBD therapies





## Please help with this

- If your site is already set up – please bash through refresh ASAP!
- If not yet set up – pls talk to me after + email
  - [Laetitia.pele@bioresource.nihr.ac.uk](mailto:Laetitia.pele@bioresource.nihr.ac.uk) (best)
  - Or [ibd@bioresource.nihr.ac.uk](mailto:ibd@bioresource.nihr.ac.uk)