



Creating a Secure, Accessible National Healthcare Data Capture for Translational Research

NHS
National Institute for
Health Research

IBD BioResource part of the NIHR BioResource

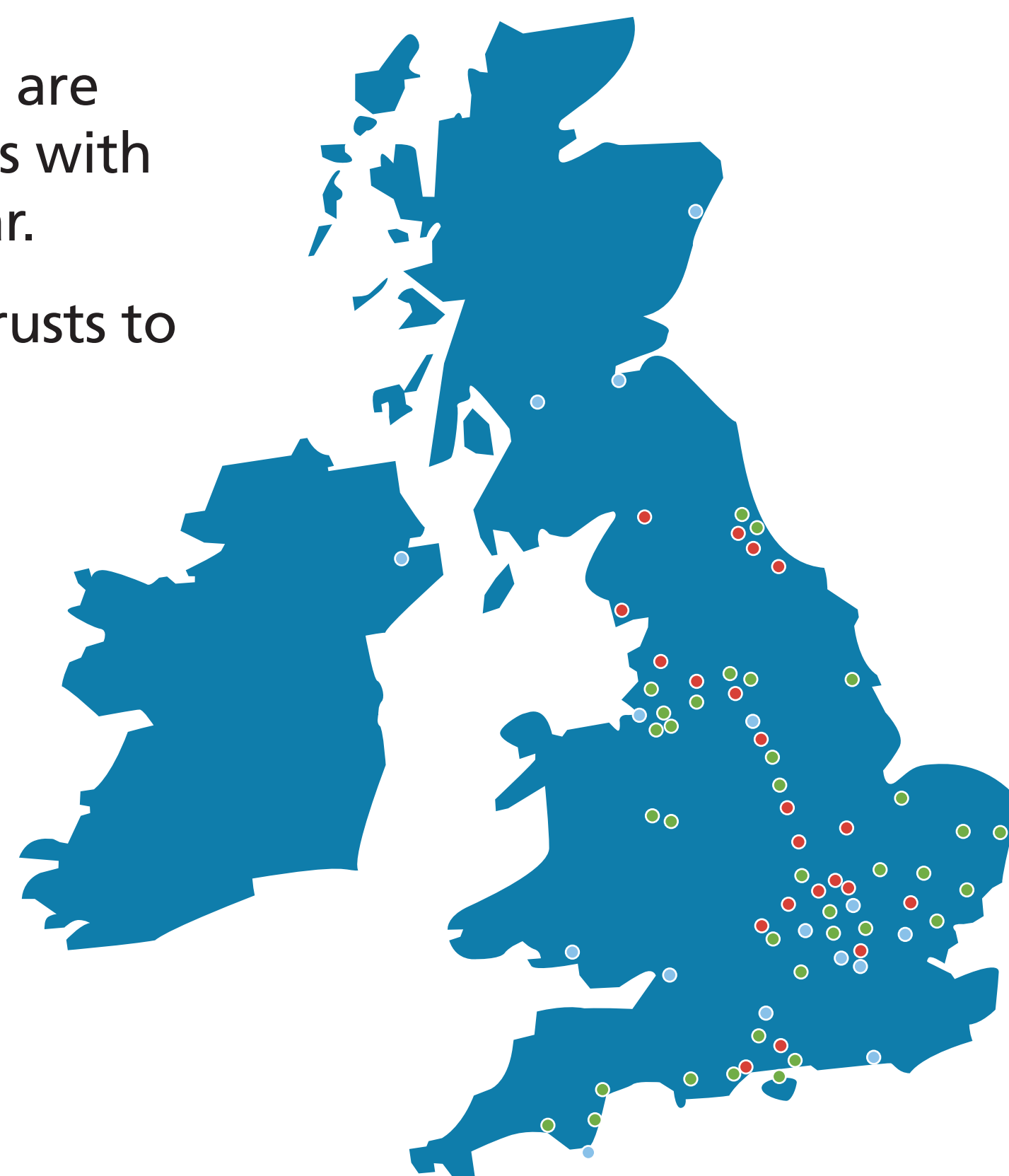
The IBD BioResource recruits volunteers from IBD clinics nationwide recallable into research studies. The collected samples and data are used to inform recall of individuals. This will expedite research into Crohn's disease and Ulcerative Colitis and enhance the overall management of disease. It was essential to design a platform to collect data in a consistent manner.

Participating NHS sites

Over 30 different NHS trusts are already recruiting volunteers with around 3,000 recruited so far.

Anticipating up to 90 NHS trusts to participate in the future.

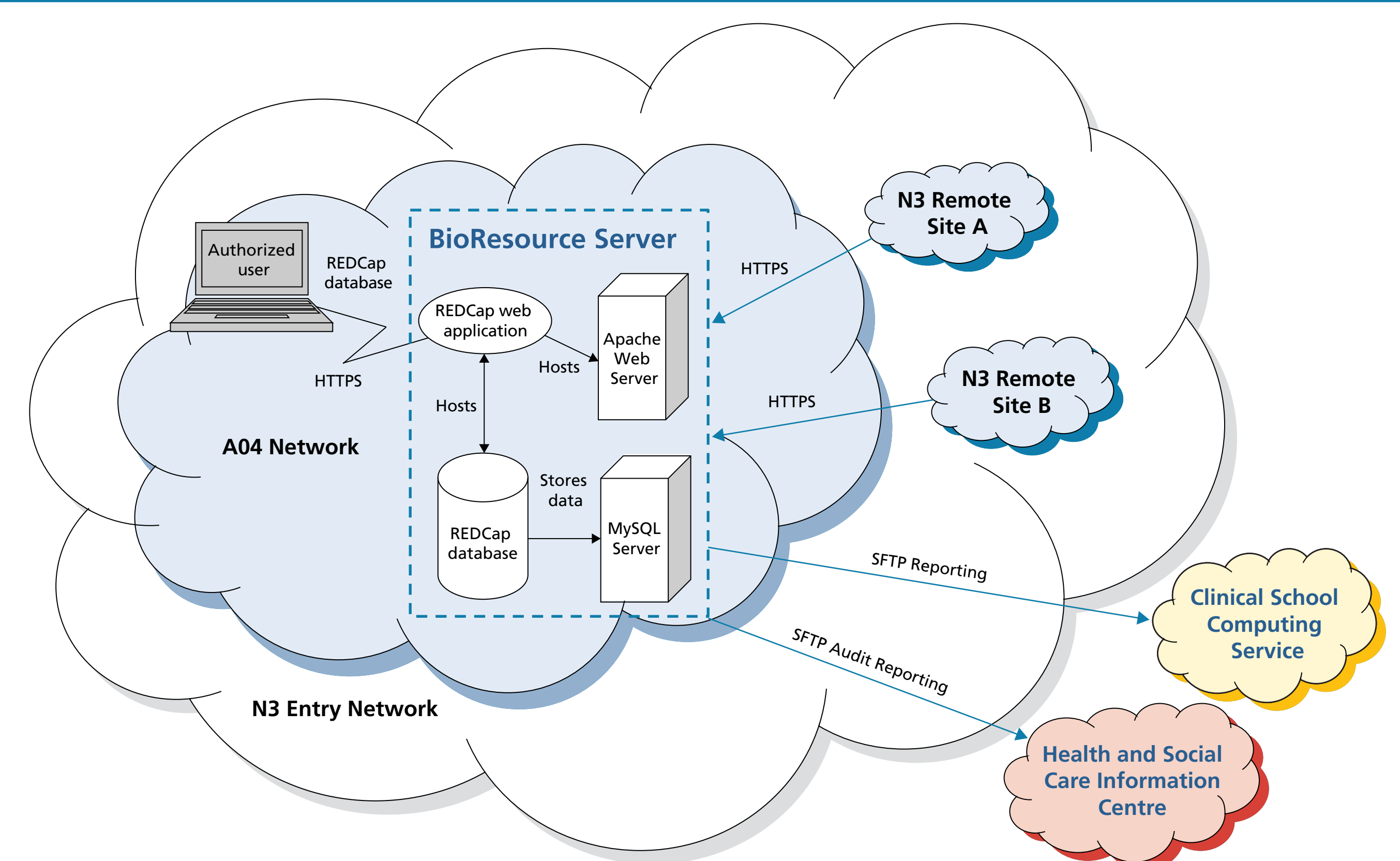
IBD BioResource sites:
Green = open
Red = opening soon
Blue = expressed interest to participate



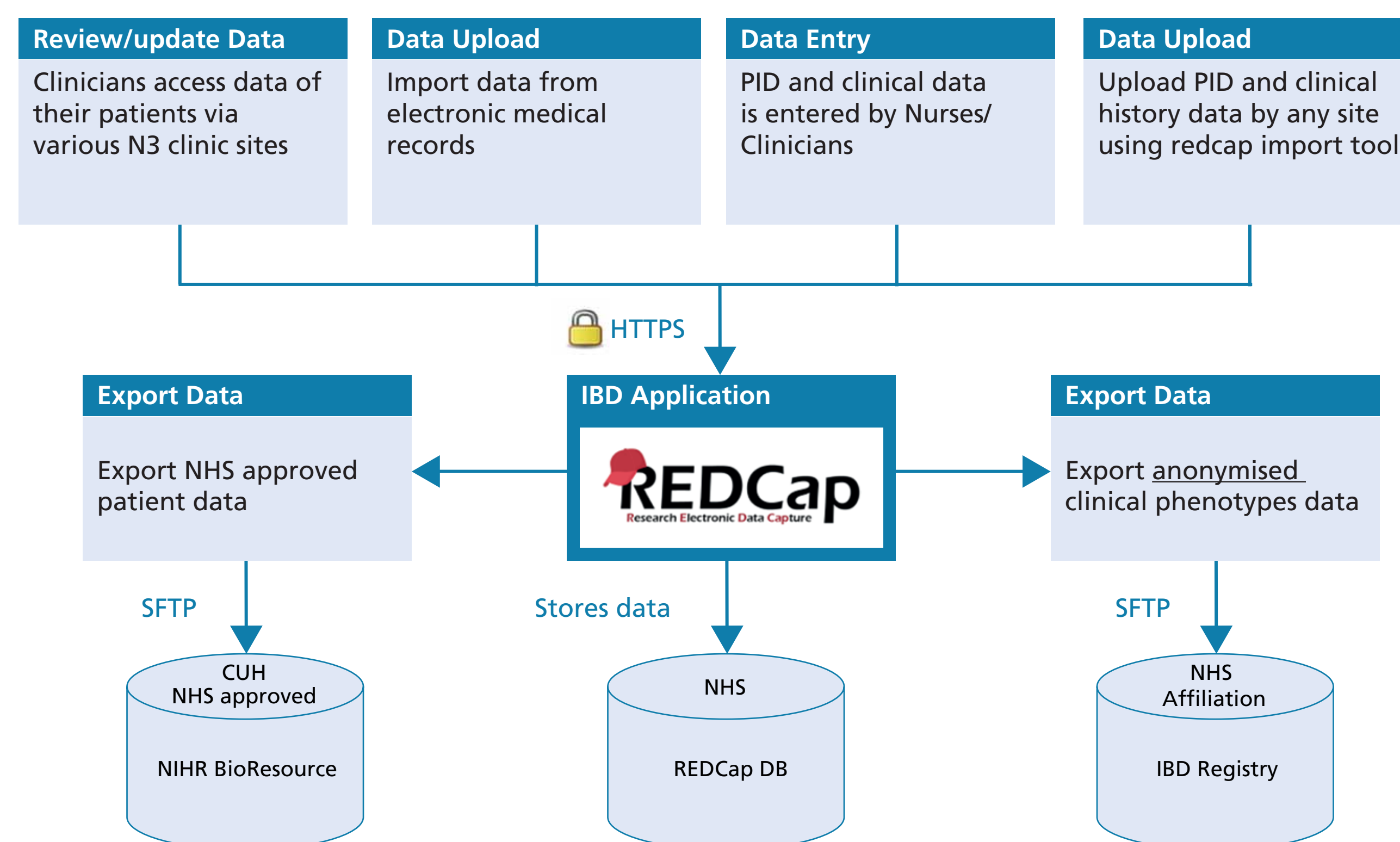
Platform objectives

- Accessible specifically across multiple NHS sites
- Easy to use by different professionals e.g. nurses, clinicians
- Easy reporting facilities
- Ease of collaboration using import/export functionality

System Architecture



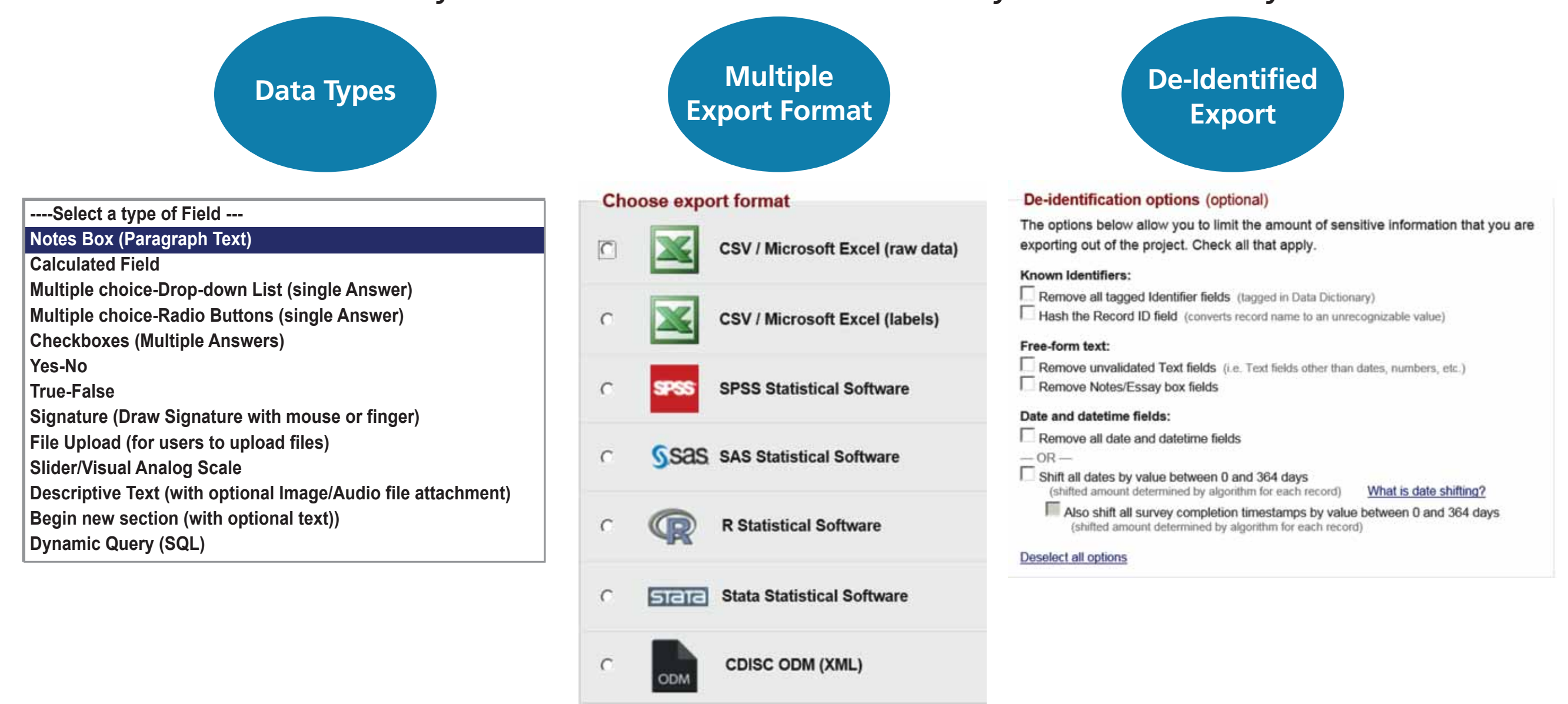
Data Flow



Tools

REDCap is:

- Web based software used to create and manage clinical research databases and surveys
- Developed as a tool to help researchers collect and manage data effectively and reasonably



Application Programming Interface API

API: A method for software programs to ask for and import/export data into or from REDCap project

SUMMARY REPORT

Name: Donald Duck Date of birth: 03-09-1986
IBD diagnosis / Year: Crohn's disease / 2010
Macroscopic Extent: Ileal, Colonic
Perianal Disease: Simple fistula
Behaviour: B3 (internal penetrating)
Does the patient currently have a stoma? Yes
Associated Conditions: Primary Sclerosing Cholangitis, Erythema Nodosum
Smoking Status at time of diagnosis of IBD: Smoking at diagnosis
Current Smoking Status: Not smoking
Current Medication: Coamoxiclav
Surgical History:

Date	Operation
03-09-2014	Ileo-caecal resection (Right hemicolectomy)
09-09-2015	Ileal / jejunal resection

Medication History:

Medication	Start date	Stop date	Effective ?	Adverse reaction(s)?	Comment
Azathioprine	2012	2012	Worked for < 12 months then lost response	Pancreatitis	
Infliximab	2013	2014	Worked for > 12 months then lost response	Anaphylaxis or anaphylactoid reaction	In PANITS
IV steroids	2014		Yes (no 'rescue' therapy needed)		
Coamoxiclav	2014		Yes	Fever	For perianal sepsis

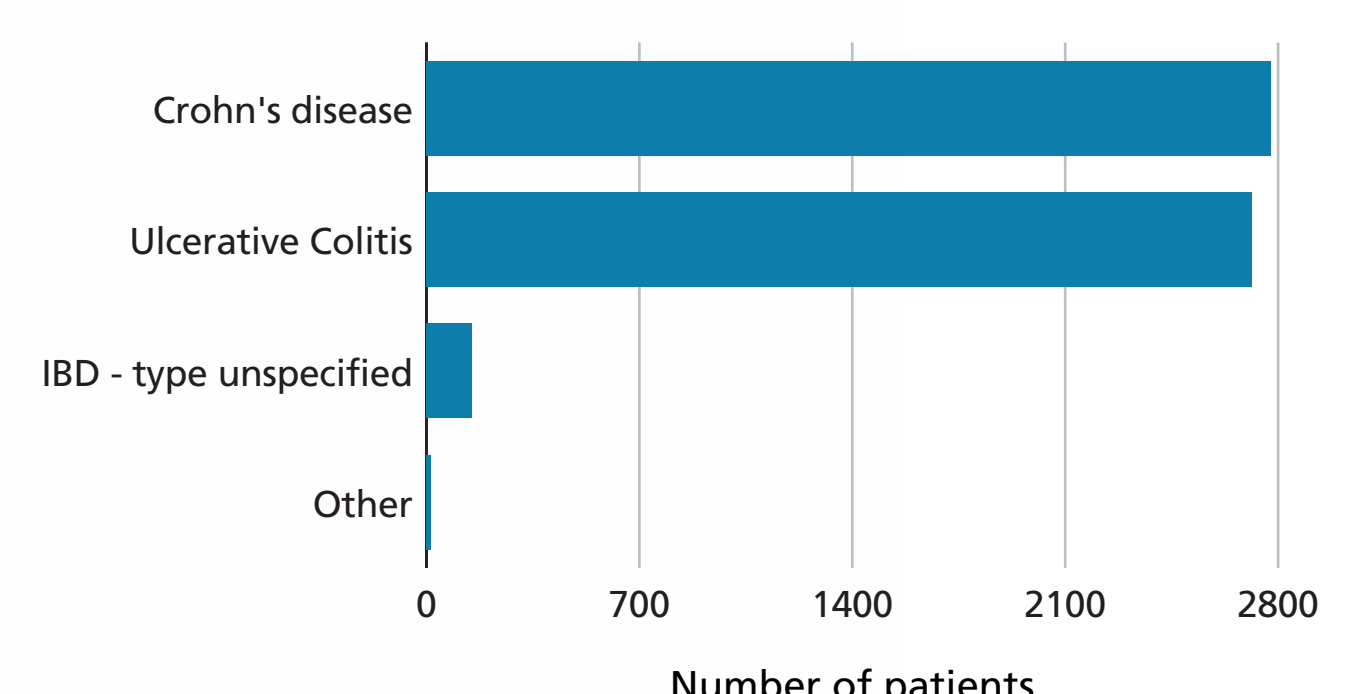
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Using a secure API
to produce a summary
for clinical data

Reports and Statistics

Number of patients who have had Azathioprine and/or Mercaptopurine

Diagnosis	Azathioprine	Mercaptopurine
Crohn's	935	228
UC	480	114
IBDU	25	10
Other	4	1



Number of patients who have had Methotrexate and/or Ciclosporin

Diagnosis	Methotrexate	Ciclosporin
Crohn's	168	11
UC	56	45
IBDU	2	1
Other	1	0

Number of patients who have each surgery type for Crohn's disease

Operation	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total
OP_1	55	6	20	6	68	4	166	39	6	8	43	43	14	80	558
OP_2	11	2	8	3	56	7	34	12	7	18	31	24	10	94	317
OP_3	9	0	4	2	16	3	11	2	4	8	20	8	8	51	146
OP_4	1	0	1	2	11	2	2	0	1	4	5	4	7	24	64
OP_5	1	0	0	0	2	1	1	1	1	1	2	4	0	9	23

1- Colectomy and ileostomy 2- Colectomy and ileo-anal pouch 3- Defunctioning ileostomy 4- Drainage of intra-abdominal abscess 5- Ileal / jejunal resection 6- Ileal / jejunal strictureplasty 7- Ileo-caecal resection (Right hemicolectomy) 8- Partial colectomy 9- Proctectomy 10- Strictureplasty 11- Insertion of seton suture 12- Drainage of perianal abscess 13- Perianal fistula repair 14- Other