United Kingdom

NIHR IBD Bioresource: Participants Consent details

Study Documentation

September 9, 2021

Metadata Production

Table of Contents

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Overview

Identification	IBD_BioResource_Consent_v1.0
Version	1.0

Abstract

The NIHR BioResource records consent dates and versions for each and every participant consent event. We also record use of opt-ins and opt-outs including pre-GDPR. This permits us to manage data releases in line with participants' expectations.

Since participants can be asked for consent multiple times, for any given participant, the consent date appearing on this dataset is always the latest available.

The NIHR IBD Bioresource comprises ~30k participants with Inflammatory Bowel Disease (IBD), which include the members of the HDR UK IBD Hub. The NIHR BioResource records consent details – form, version and date - from participants at many points of recontact. In addition, participants are empowered to contact the study directly to express their preferences. The primary use of consent records is as an exclusion criterion when participants are invited to take part in experimental medicine studies. However, consent is also factored in to the release of samples and data for sample-only and data-only studies. One implication, is that data releases have freezes that capture a snapshot of the current consent statuses. How the withdrawal process is managed, and implications for whether data can be removed rapidly from already published datasets is described in our Participant Privacy Notice, online at https://bioresource.nihr.ac.uk/privacy

The current consent records includes those participants, active or deceased, that have consented and not opted out frrom the study at any date previous to that in which the data dictionary has been released.

More information is available here:
https://web.www.healthdatagateway.org/dataset/44ca2cf8-679e-447c-a9eb-55b32159679a

This documentation refers to a draft version of the dataset.

Scope & Coverage

Countries	United Kingdom

Geographic Coverage
United Kingdom (https://www.geonames.org/2635167/united-kingdom.html)

Files Description

Dataset contains 1 file(s)

IBD_BioResource_Consent_v1.0	
# Cases	34353
# Variable(s)	6

Variables List

Dataset contains 6 variable(s)

#	Name	Label	Type	Format	Valid	Invalid	Question
File IBD_BioResource_Consent_v1.0							
1	Consent_..	Consent_date	discrete	character	34353	-	Date of consent with format YYYY-MM-YY
2	Consent_..	Consent_version	discrete	character-44	34353	0	Version of the consent form used
3	Consent_..	Consent_year	discrete	character	34353	-	Year of consent with format YYYY
4	Informat ..	Information_leaflet_version	discrete	character-45	34353	0	Version of the consent leaflet used, that accompanies the consent form (8 versions)
5	particip ..	participant_id	discrete	character-10	34353	0	Identifier (unique)
6	Voluntee ..	Volunteer_status	discrete	character-8	34353	0	Status of participant (only Active and Deceased appearing on dictionary)

Variables Description

Dataset contains 6 variable(s)

File : IBD_BioResource_Consent_v1.0

Consent_date: Consent_date

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/ W]	[Valid=34353 /-]
Literal question	Date of consent with format YYYY-MM-YY

Consent_version: Consent_version

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/ W]	[Valid=34353 /-] [Invalid=0 /-]
Literal question	Version of the consent form used

Value	Label	Cases	Percentage
IBD Inception Cohort - V2 07/10/2015		26	0.1%
IBD Inception Cohort - V3 12/09/2016		27	0.1%
IBD Inception Cohort - V4 3/10/2017		197	0.6%
IBD Inception Cohort - V4 3/10/2017 inferred		7	0.0%
IBD Inception Cohort - v5 22/01/2019		172	0.5%
IBD Main Cohort - V2 07/10/2015		11	0.0%
IBD Main Cohort - V2.1 01/02/2016		25	0.1%
IBD Main Cohort - V3 12/09/2016		404	1.2%
IBD Main Cohort - V4 03/10/2017		16256	47.3%
IBD Main Cohort - V4 03/10/2017 inferred		8402	24.5%
IBD Main Cohort - v5 22/01/2019		8824	25.7%
NULL		2	0.0%

Warning: these figures indicate the number of cases found in the data file. They cannot be interpreted as summary statistics of the population of interest.

Consent_year: Consent_year

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/ W]	[Valid=34353 /-]
Literal question	Year of consent with format YYYY

File : IBD_BioResource_Consent_v1.0

Consent_year: Consent_year

Value	Label	Cases	Percentage
2016		49	0.1%
2017		326	0.9%
2018		18343	53.4%
2019		12518	36.4%
2020		2702	7.9%
2021		415	1.2%

Warning: these figures indicate the number of cases found in the data file. They cannot be interpreted as summary statistics of the population of interest.

Information_leaflet_version: Information_leaflet_version

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/ W]	[Valid=34353 /-] [Invalid=0 /-]
Literal question	Version of the consent leaflet used, that accompanies the consent form (8 versions)

Value	Label	Cases	Percentage
NULL		1	0.0%
National IBD - V1 28/10/2015		35	0.1%
National IBD - V2 15/09/2016		406	1.2%
National IBD - V5 3/10/2017		24656	71.8%
National IBD Inception cohort - V5 3/10/2017		205	0.6%
National IBD Inception cohort - v1 28/10/2015		28	0.1%
National IBD Inception cohort - v2 15/09/2016		26	0.1%
National IBD Inception cohort - v6 22/01/2019		172	0.5%
National IBD Main cohort - v6 22/01/2019		8824	25.7%

Warning: these figures indicate the number of cases found in the data file. They cannot be interpreted as summary statistics of the population of interest.

participant_id: participant_id

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/ W]	[Valid=34353 /-] [Invalid=0 /-]
Literal question	Identifier (unique)

Volunteer_status: Volunteer_status

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/ W]	[Valid=34353 /-] [Invalid=0 /-]
Literal question	Status of participant (only Active and Deceased appearing on dictionary)

Value	Label	Cases	Percentage
Active		33914	98.7%

File : IBD_BioResource_Consent_v1.0

Volunteer_status: Volunteer_status

Value	Label	Cases	Percentage
Deceased		439	1.3%

Warning: these figures indicate the number of cases found in the data file. They cannot be interpreted as summary statistics of the population of interest.