NIHR BioResource for Translational Research

IBD NIHR BioResource Demographics

Study Documentation

Metadata Production

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Overview	
Identification	ibd_gutreaction_demographics
Version	4.0.0

Abstract

The NIHR BioResource acquires broad demographics – e.g. age, sex, ethnicity - from participants at recruitment. This is used to pre-screen or match participants when inviting them to take part in experimental medicine studies

The NIHR IBD Bioresource comprises ~34k participants with Inflammatory Bowel Disease (IBD), which include the members of the HDR UK IBD Hub. The NIHR BioResource acquires demographic details – e.g. age, sex, ethnicity - from participants at recruitment. This is used to pre-screen or match participants when inviting them to take part in experimental medicine studies. De-identified versions of this data are available to researchers investigating the feasibility of future studies.

Publications (with DOIs) are listed at: https://bioresource.nihr.ac.uk/publications/

Link to the Health Data Research (HDR UK) Innovation Gateway: https://web.www.healthdatagateway.org/dataset/b4121feb-f91b-4e20-a19b-fa49c7a5c1c1

This documentation is a draft version of the dataset. Many of the NULLs arise from checkboxes that are not ticked, but also from forms or part-forms being missing. This will be resolved in future versions.

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

Producers & Spons	sors
Primary Investigator(s)	NIHR BioResource for Translational Research

Data Collection					
Data Collection Mode	Dataset time lag: 1-2 MONTHS				
	Typical age range: 18-85				
	Physical sample availability: DNA, PLASMA, SERUM				
	Follow-up: 1 - 10 YEARS				
	Data models: I2B2				
	Language: en				
	Format: text/csv				

Purpose: STUDYSource

ELECTRONIC SURVEY: PAPER BASED

Collection situation: CLINIC, COMMUNITY, HOME

Access information: https://bioresource.nihr.ac.uk/using-our-bioresource

Processing time: 2-6 MONTHS

Jurisdiction: GB-GBN

Limitations: RESEARCH USE ONLY

Data Controller: Cambridge University Hospitals NHS Foundation Trust (CUH)

Data Processor: Data processors are NIHR BioResource staff, others with Letters of Access to CUH

and approved members of staff at the data centre (AIMES, https://aimes.uk/)

Files Description

Dataset contains 1 file(s)

IBD NIHR BioResource Demographic		
# Cases	34708	
# Variable(s)	18	

Variables List

Dataset contains 18 variable(s)

File	File IBD NIHR BioResource Demographic						
#	Name	Label	Туре	Format	Valid	Invalid	Question
1	Agebands	Age Bands	discrete	character-10	34707	0	-
2	Alcoholc	Alcohol Consumption	discrete	character-30	34707	0	Do you drink alcohol? If yes, how many units per week (approx)?
3	BMIBands	BMI Bands	discrete	character-30	34707	0	-
4	<u>BMI</u>	BMI	discrete	character-10	-	-	-
5	Currents	Current smoker	discrete	character-4	34707	0	Do you smoke?
6	Dietaryh	Dietary Habits	discrete	character-11	34707	0	Do you have a specific diet? None, Vegetarian, Pescetarian, Vegan, Other
7	Ethnicit	Ethnicity Group	discrete	character-30	34707	0	Ethnicity
8	Ethnicity	Ethnicity	discrete	character-4	0	0	Ethnicity
9	Exsmoker	Ex-smoker	discrete	character-4	34707	0	Did you smoke in the past?
10	Gender	Gender	discrete	character-4	34707	0	Which gender do you identify with?
11	Handpref	Hand Preference	discrete	character-5	34707	0	Are you right or left handed?
12	HeightBa	Height Bands	discrete	character-30	34707	0	Height - in metres/centimetres
13	Height	Height	discrete	character-10	-	-	Height - in metres/centimetres
14	Nonsmoker	Non-smoker	discrete	character-4	34707	0	Non-Smoker
15	Particip	Participant ID	discrete	character-10	34707	0	-
16	Smokerga	Smoker Gave Up	discrete	character-4	-	-	What year did you give up smoking? (yyyy)
17	Weight	Weight	discrete	character-30	-	-	Weight - in kilograms
18	WeightBa	Weight Bands	discrete	character-30	34707	0	Weight - in kilograms

Variables Description

Dataset contains 18 variable(s)

Agebands: Age Bands

Information	[Type= discrete] [Format=character] [Missing=*]	
Statistics [NW/ W] [Valid=34707 /-] [Invalid=0 /-]		
Definition	Calculated from current year - year of birth	

Value	Label	Cases	Percentage
0-14		14	0.0%
15-19		221	0.6%
20-24		1814	5.2%
25-29		2949	8.5%
30-34		3308	9.5%
35-39		3445	9.9%
40-44		3171	9.1%
45-49		3128	9.0%
50-54		3236	9.3%
55-59		3212	9.3%
60-64		2802	8.1%
65-69		2402	6.9%
70-74		2315	6.7%
75-79		1492	4.3%
80+		925	2.7%
NULL		273	0.8%

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.

${\it \#}\, Alcohol consumption: Alcohol \,\, Consumption$

Information	Γype= discrete] [Format=character] [Missing=*]	
Statistics [NW/W]	/alid=34707 /-] [Invalid=0 /-]	
Pre-question	Alcohol	
Literal question	Do you drink alcohol? If yes, how many units per week (approx)?	
Concepts	Alcohol intake (observable entity) - 160573003	

Value	Label	Cases	Percentage
0-5	A1	326	0.9%
6-10	A2	129	0.4%
11-15	A3	68	0.2%
16-20	A4	58	0.2%
21-25	A5	17	0.0%
26-30	A6	20	0.1%
>30	A7	13	0.0%
New Guideline 0-5	B1	7153	20.6%
New Guideline 6-10	B2	3252	9.4%
New Guideline 11-15	В3	1967	5.7%
New Guideline 16-20	B4	1156	3.3%

Alcoholconsumption: Alcohol Consumption

Value	Label	Cases	Percentage
New Guideline 21-25	B5	725	2.1%
New Guideline 26-30	B6	436	1.3%
New Guideline >30	В7	340	1.0%
NULL	C	19047	54.9%

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.

#BMIBands: BMI Bands

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Definition	Derived value
Pre-question	Demographics - Details of participant
Concepts	Body mass index (observable entity)-60621009

Value	Label	Cases	Percentage
< 18.5	1: underweight	518	1.5%
>= 18.5 and <= 24.9	2: healthy weight	8766	25.3%
> 24.9 and <= 29.9	3: overweight	6988	20.1%
>29.9 and <= 39.9	4: obese	4066	11.7%
> 39.9	5: extremely obese	530	1.5%
NULL	6: NULL	13839	39.9%

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.

#BMI: BMI

Information	[Type= discrete] [Format=character] [Missing=*]
Definition	Derived value
Pre-question	Demographics - Details of participant
Concepts	Body mass index (observable entity)-60621009

Currentsmoker: Current smoker

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Pre-question	Smoking
Literal question	Do you smoke?
Concepts	Smoker (finding) - 77176002

Value	Label	Cases	Percentage
Yes		2172	6.3%
NULL		32535	93.7%

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.

Dietaryhabits: Dietary Habits

ı	Dictary nations. Dictary nations	
	Information	[Type= discrete] [Format=character] [Missing=*]

	111111	BioResource Demographi					
# Dietaryhabi	ts: Dietar	y Habits					
Statistics [NW/ V	tistics [NW/ W] [Valid=34707 /-] [Invalid=0 /-]						
Pre-question		Demographics - Details of participant					
Literal question		Do you have a specific diet? None, Vegetarian, Pescetarian, Vegan, Other					
Concepts		Diet followed (observable entity)-230125005	Diet followed (observable entity)-230125005				
Value	Label		Cases	Percen	itage		
Vegetarian			776	2.2%			
Vegan			171	0.5%			
Pescetarian			345	1.0%			
Other			1813	5.2%			
None			19552		56.3%		
NULL			12050		34.7%		
Narning: these figures	indicate the nun	nber of cases found in the data file. They cannot be interpreted a	s summary statistics of the	population of interest.			
# EthnicityG1	oup: Ethi	nicity Group					
Information		[Type= discrete] [Format=character] [Missing=*]					
Statistics [NW/ V	W]	[Valid=34707 /-] [Invalid=0 /-]					
Pre-question		Demographics - Details of participant					
Literal question		Ethnicity					
Concepts Ethnic backg		Ethnic background (finding) - 398089004					
Value	Label		Cases	Percen	itage		
WHITE OR WHITE BRITISH	1: WHITE	OR WHITE BRITISH	30573		88.1%		
ASIAN OR BRITISH ASIAN	2: ASIAN	OR BRITISH ASIAN	1333	3.8%			
BI ACK	3: BLACK	OR BLACK BRITISH	163	0.5%			
OR BLACK				1 20/			
BLACK OR BLACK BRITISH MIXED	4: MIXED		451	1.3%			
OR BLACK BRITISH	4: MIXED 5: OTHER	ETHNIC	451 121	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC							
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL	5: OTHER 6: NOT ST 7: NULL	ATED	121 258 1808	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL Warning: these figures	5: OTHER 6: NOT ST 7: NULL indicate the num		121 258 1808	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL Warning: these figures	5: OTHER 6: NOT ST 7: NULL indicate the num	ATED ther of cases found in the data file. They cannot be interpreted a	121 258 1808 is summary statistics of the	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL Warning: these figure: # Ethnicity: F	5: OTHER 6: NOT ST 7: NULL indicate the nun	ATED ther of cases found in the data file. They cannot be interpreted as [Type= discrete] [Format=character] [Missing=	121 258 1808 is summary statistics of the	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL Warning: these figures: # Ethnicity: E Information Statistics [NW/ V	5: OTHER 6: NOT ST 7: NULL indicate the nun	ATED ther of cases found in the data file. They cannot be interpreted as [Type= discrete] [Format=character] [Missing= [Valid=0 /-] [Invalid=0 /-]	121 258 1808 is summary statistics of the	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL Warning: these figures # Ethnicity: F Information Statistics [NW/V]	5: OTHER 6: NOT ST 7: NULL indicate the nun	ATED ther of cases found in the data file. They cannot be interpreted as [Type= discrete] [Format=character] [Missing= [Valid=0 /-] [Invalid=0 /-] Demographics - Details of participant	121 258 1808 is summary statistics of the	0.3%			
OR BLACK BRITISH MIXED OTHER ETHNIC NOT STATED NULL	5: OTHER 6: NOT ST 7: NULL indicate the nun	ATED ther of cases found in the data file. They cannot be interpreted as [Type= discrete] [Format=character] [Missing= [Valid=0 /-] [Invalid=0 /-]	121 258 1808 is summary statistics of the	0.3%			

[Type= discrete] [Format=character] [Missing=*]

[Valid=34707 /-] [Invalid=0 /-]

Information

Statistics [NW/W]

#Exsmoker: Ex-smoker

Pre-question	Smoking
Literal question	Did you smoke in the past?
Concepts	Ex-smoker (finding) - 8517006

Value	Label	Cases	Percentage
Yes		9890	28.5%
NULL		24817	71.5%

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.

Gender: Gender

- a	m
Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Pre-question	Demographics - Details of participant
Literal question	Which gender do you identify with?
Concepts	Gender (observable entity) - 263495000

Value	Label	Cases	Percentage
m	Male	16493	47.5%
f	Female	17932	51.7%
NULL		282	0.8%

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.

Handpreference: Hand Preference

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Literal question	Are you right or left handed?
Concepts	Hand preference (observable entity) - 246559009

Value	Label	Cases	Percentage
Both	1: Both	250	0.7%
Left	2: Left	2544	7.3%
Right	3: Right	19924	57.4%
NULL	4: NULL	11989	34.5%

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.

HeightBands: Height Bands

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Pre-question	Demographics from the Health & Lifestyle Questionnaire
Literal question	Height - in metres/centimetres
Concepts	Body height measure (observable entity) - 50373000

Value	Label	Cases	Percentage
0-1.60		3239	9.3%
1.60-1.69		7264	20.9%
1.70-1.79		6804	19.6%
1.80-1.89		3490	10.1%

# HeightBands:	Height Bands
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Value	Label	Cases	Percentage
1.90-1.99		469	1.4%
>= 2.0		49	0.1%
NULL		13392	38.6%

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.

Height: Height

Information	[Type= discrete] [Format=character] [Missing=*]
Pre-question	Demographics from the Health & Lifestyle Questionnaire
Literal question	Height - in metres/centimetres
Concepts	Body height measure (observable entity) - 50373000

Nonsmoker: Non-smoker

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Pre-question	Smoking
Literal question	Non-Smoker
Concepts	Non-smoker (finding) - 8392000

Value	Label	Cases	Percentage
Yes		9503	27.4%
NULL		25204	72.6%

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: Participant ID

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]

Smokergaveup: Smoker Gave Up

Information	[Type= discrete] [Format=character] [Missing=*]
Pre-question	Smoking
Literal question	What year did you give up smoking? (yyyy)
Concepts	Smoker Gave Up = 1221000175102

Weight: Weight

Information	[Type= discrete] [Format=character] [Missing=*]
Pre-question	Demographics from the Health & Lifestyle Questionnaire
Literal question	Weight - in kilograms
Concepts	Body weight (observable entity) - 27113001

#WeightBands: Weight Bands

Information	[Type= discrete] [Format=character] [Missing=*]
Statistics [NW/W]	[Valid=34707 /-] [Invalid=0 /-]
Pre-question	Demographics from the Health & Lifestyle Questionnaire
Literal question	Weight - in kilograms
Concepts	Body weight (observable entity) - 27113001

WeightBands: Weight Bands

Value	Label	Cases	Percentage	
0-49.9	W1	580	1.7%	
50-69.9	W2	8106	23.	4%
70-89.9	W3	9146		26.4%
90-109.9	W4	3506	10.1%	
110-139.9	W5	840	2.4%	
140-179.9	W6	86	0.2%	
180 or more	W7	24	0.1%	
NULL	W8	12419		35.8%