NIHR | Manchester Biomedical Research Centre

Who is taking part in our research?

Inclusivity indicators in Hearing Health research participation

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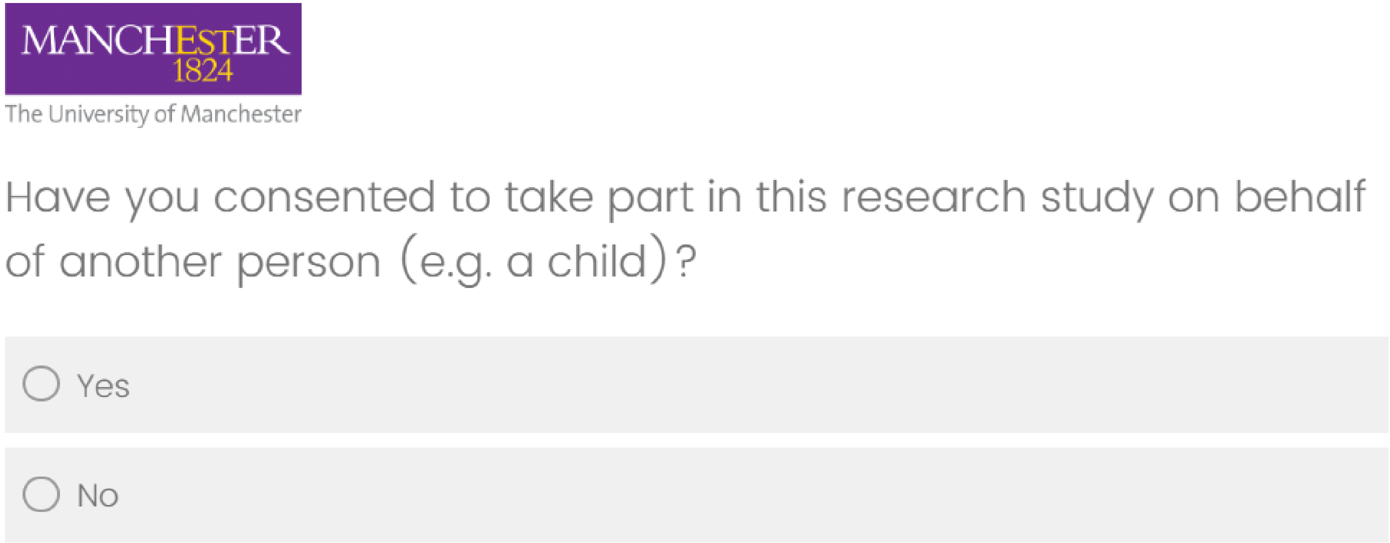
Inclusivity indicators for research participants in Hearing Health: background

- Hearing health projects have collected demographic data on an **individual** basis for many years
- In 2022 we trialled a standardised process for collecting this data to coordinate across hearing health projects
  - Coordinated use of same questionnaire
  - Same wording on ethics applications and participant documents
- Now asking for all new Hearing Health projects to collect data using the same standardised process
- Questions were based on a reduced set of questions from the NIHR workforce questions, by agreement within the group
- We have updated the questionnaire and process in consultation with central BRC Inclusive Research team

Inclusivity indicators for research participants: process

- Demographic data collected for via **fully anonymous** Qualtrics link
  - This means you <u>cannot connect these data to an ID for use in your study analysis</u>
  - Important for clarity of how data will be used and shared
  - Important for confidentiality and trust
  - Researchers should collect any demographic data they need for analysis separately
- Each study has a different Qualtrics link (but the surveys are identical)
- Typically, the link is emailed to participants to complete after the study (or is linked after completion of an online survey). Participants can also complete it during a session.
- Modified versions can be used e.g.
  - Lower cognition of participants
  - Small-scale study (e.g. brief online survey)

Participants who cannot consent



Have you consented to take part in this research study on behalf of another person (e.g. a child)?

○ Yes

○ No

- Asks about demographics of < 16 year old participants (where relevant) in addition to those of person giving consent

Inclusivity indicators for research participants: barriers?

- Some initial resistance from researchers concerned about ethical barriers
- Ethics committees and PPI groups have all been **very happy** to accept this
- In fact recent feedback has been to make the demographic survey more prominent so as not to miss out on collecting this important information

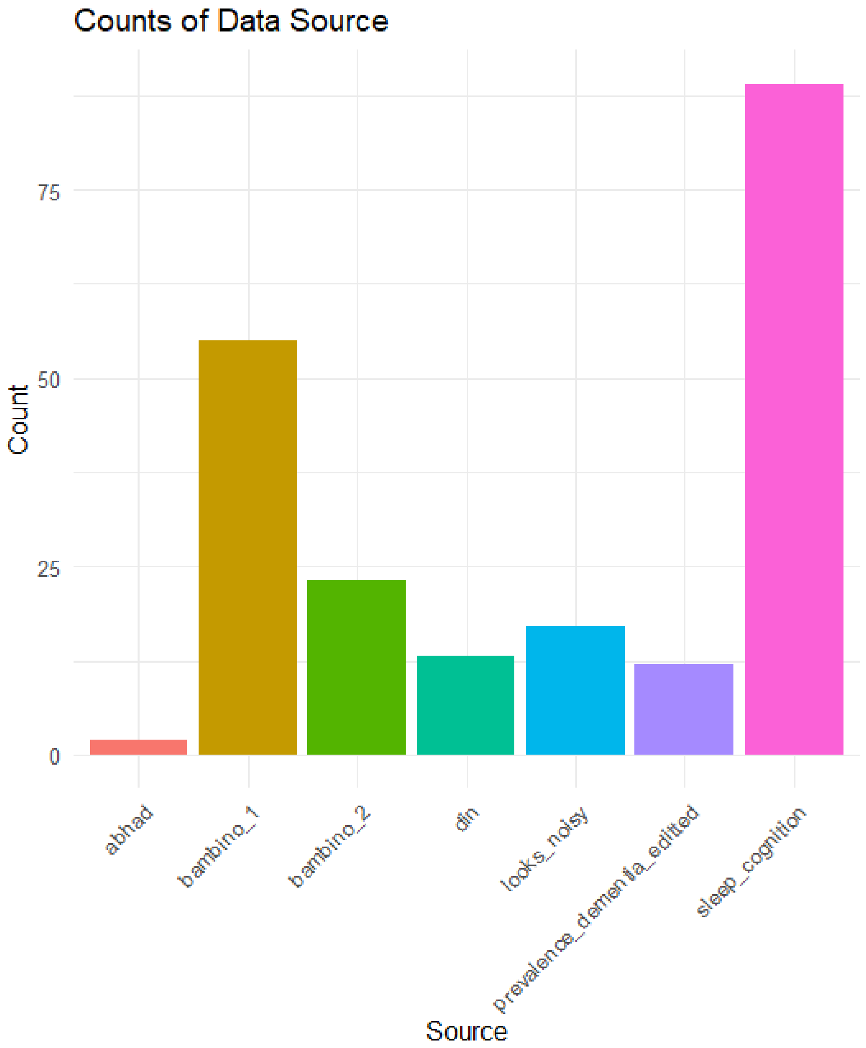
Need to collect data

Respect right to withhold data

Number of studies collecting / having collected data

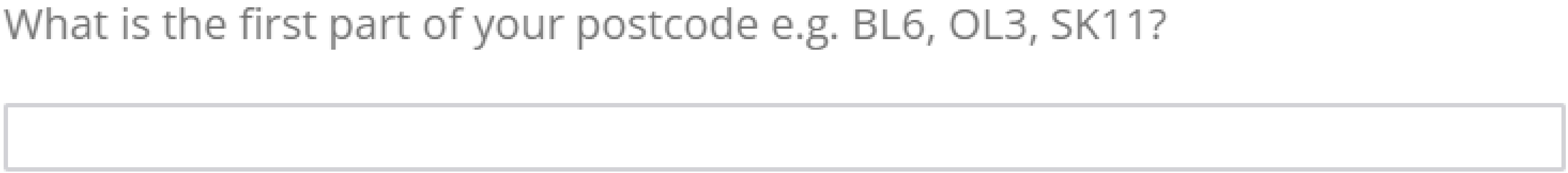
- Seven studies collecting / have collected data
  - Three more just started
  - Inclusivity data from 209 total participants
- Includes a mix of UoM and NHS ethics: no problems in either case
- Mix of online and face-to-face
- Most studies used the standard version of the questionnaire, one used easy-read modifications

Not big numbers: Need more data to know if results are representative



CAVEAT: ANALYSIS IS PRETTY BASIC AT PRESENT.

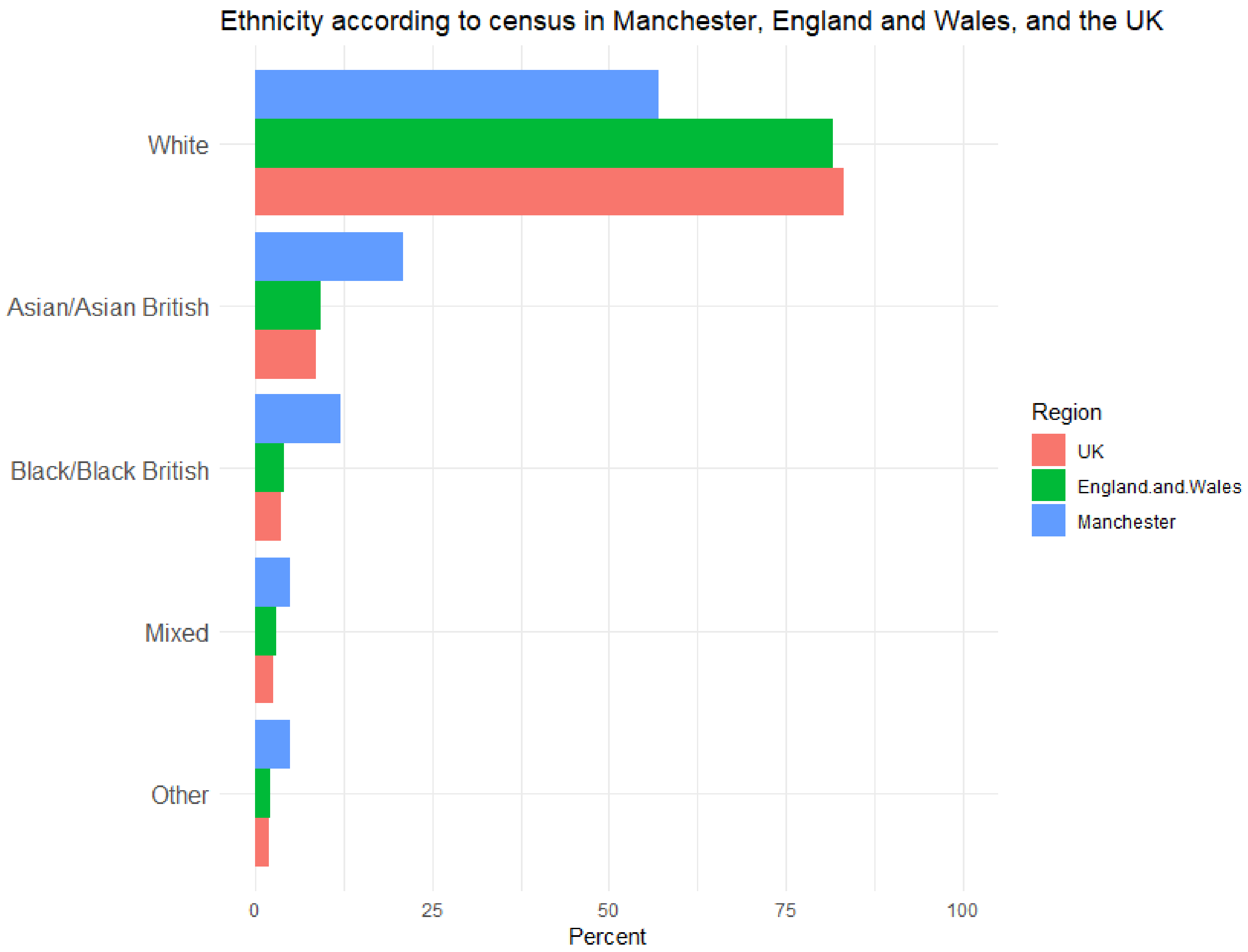
REFINEMENTS NEED TO BE ADDED, E.G. CONSIDERING TARGET POPULATIONS OF INDIVIDUAL STUDIES, RESPONSE RATES, STATISTICAL COMPARISONS ETC.



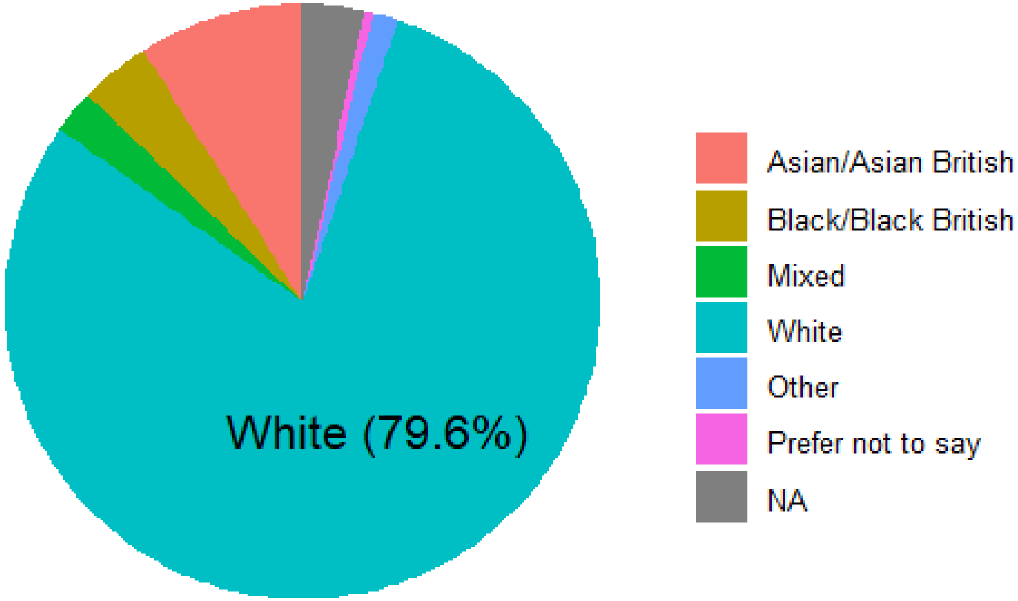
What is the first part of your postcode e.g. BL6, OL3, SK11?

- 53% of participants were from Greater Manchester
  - This was previously 90%, but has shifted due to large numbers from an online study
  - With still only a few studies collecting data we are still swayed by individual projects
- The remainder were from a wider range of postcodes across the UK

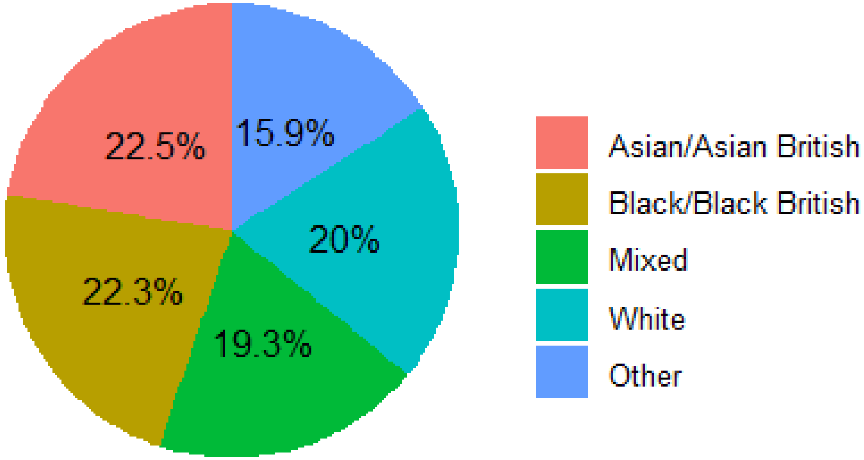
Population ethnicity according to census data



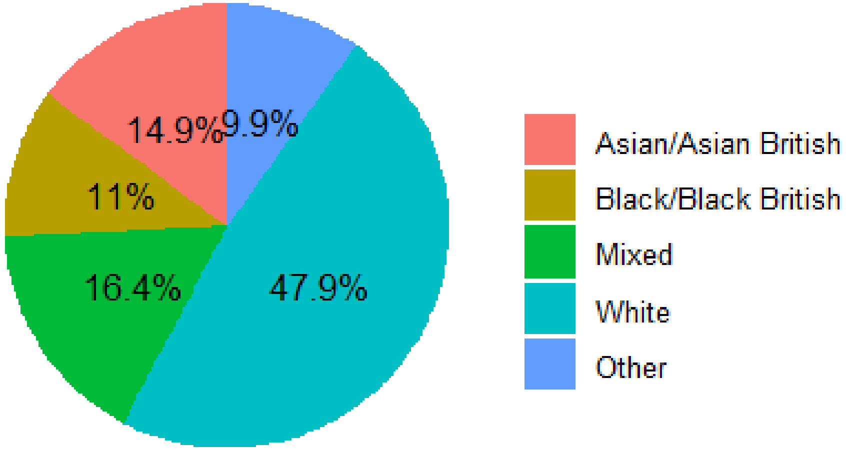
Ethnicity (our data)

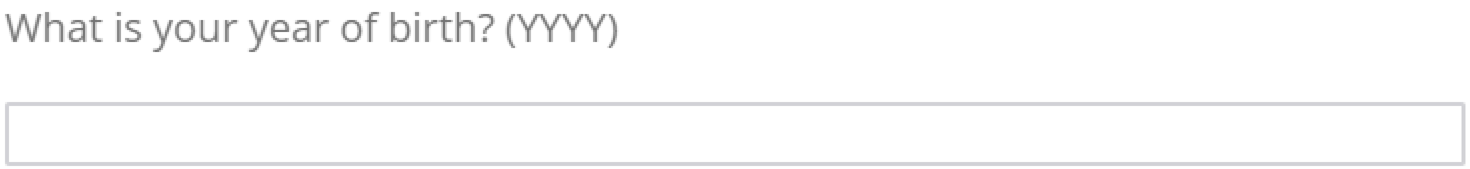


Ethnicity adjusted relative to UK census data



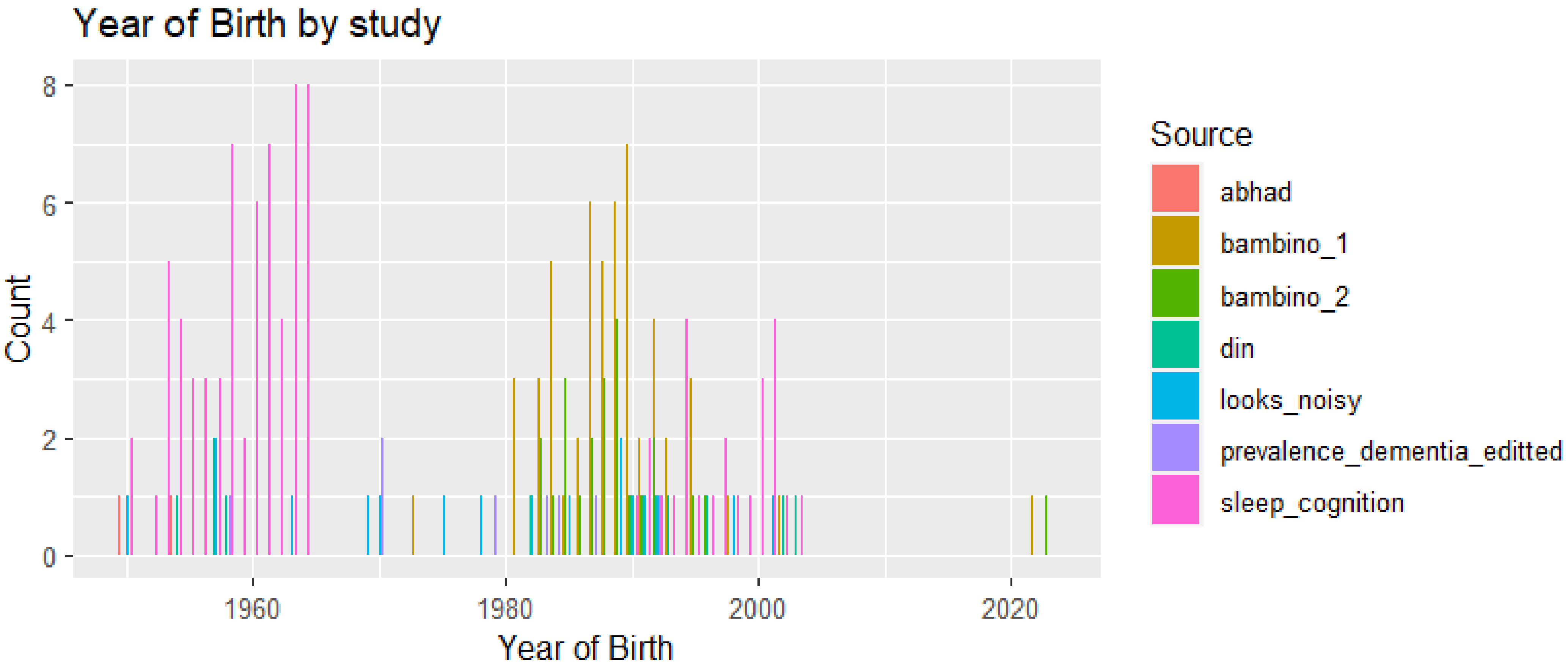
Ethnicity adjusted relative to Manchester census



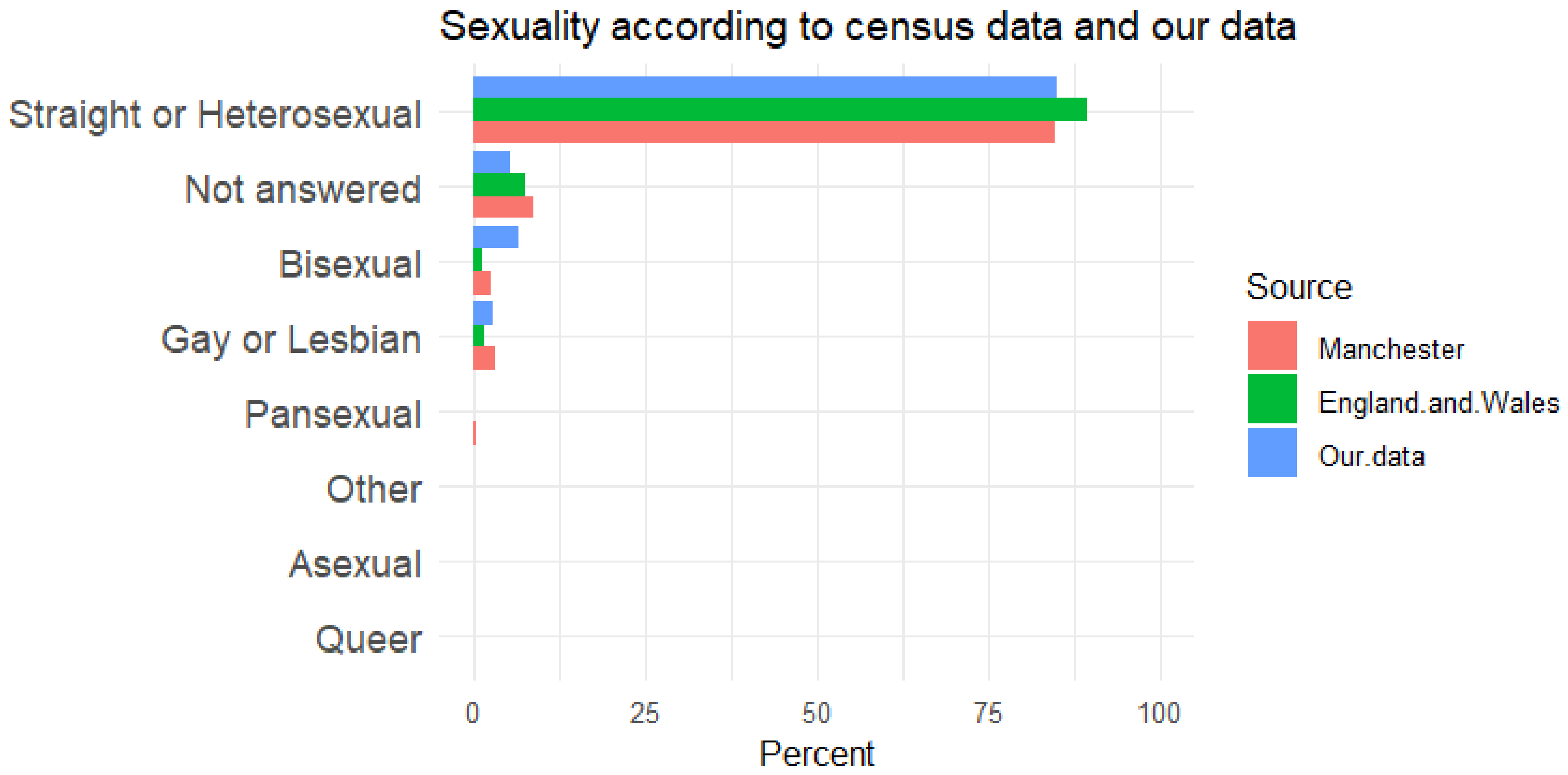


What is your year of birth? (YYYY)

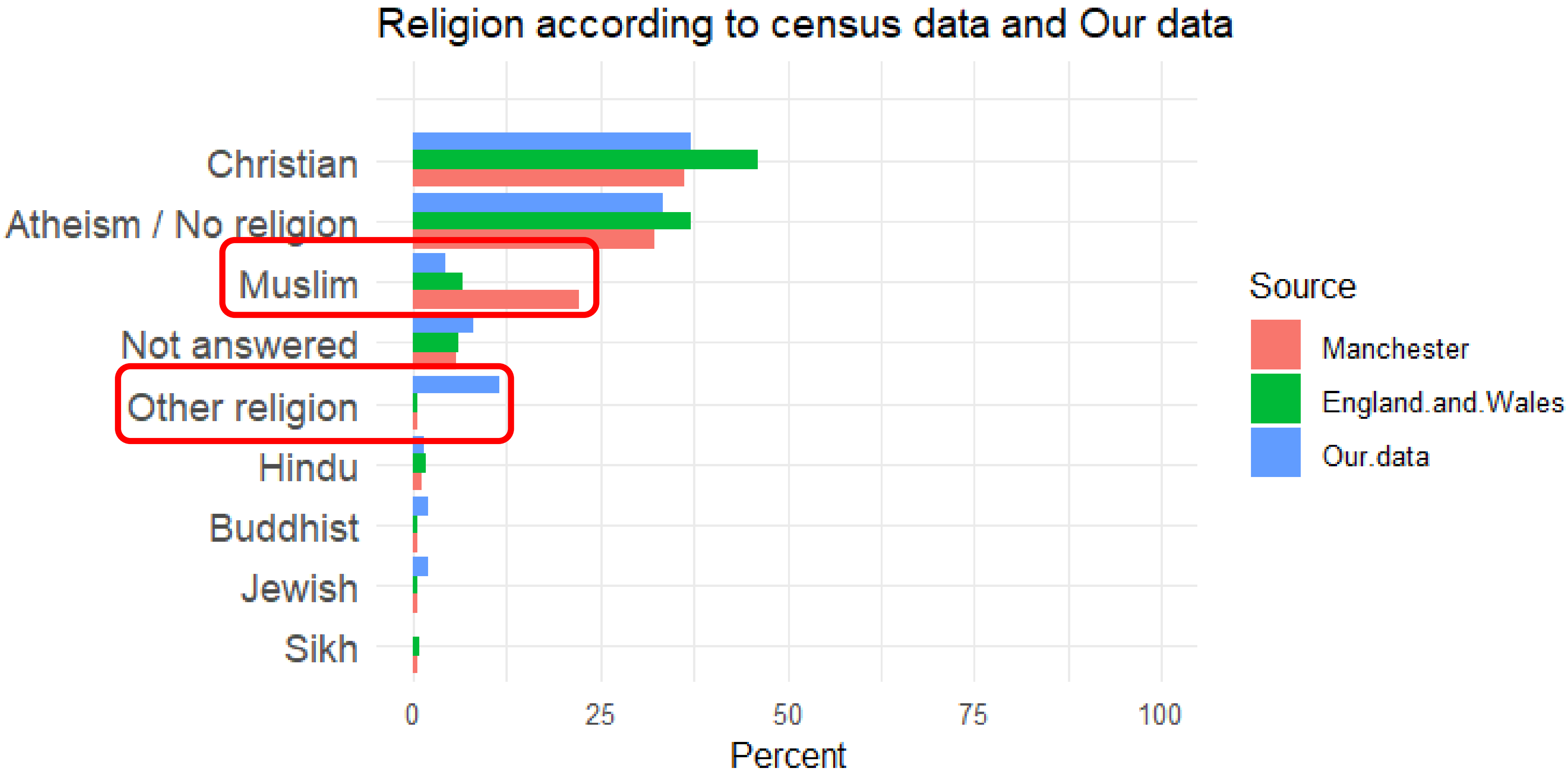
In V2 updated to “what is your age in years?”



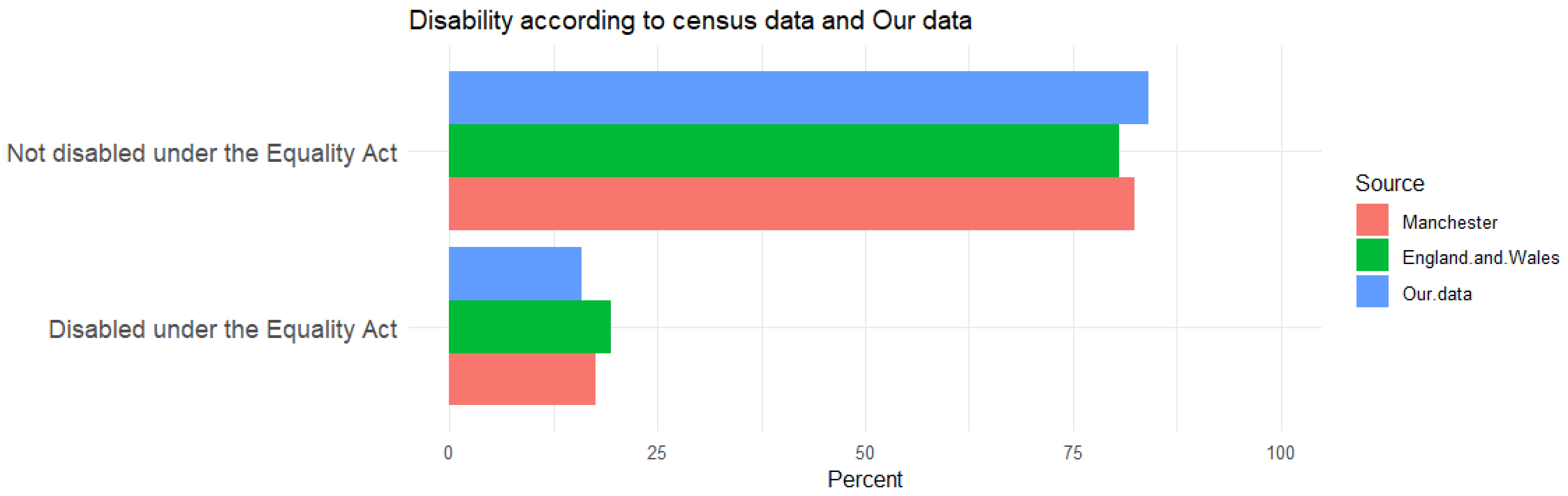
Sexual orientation



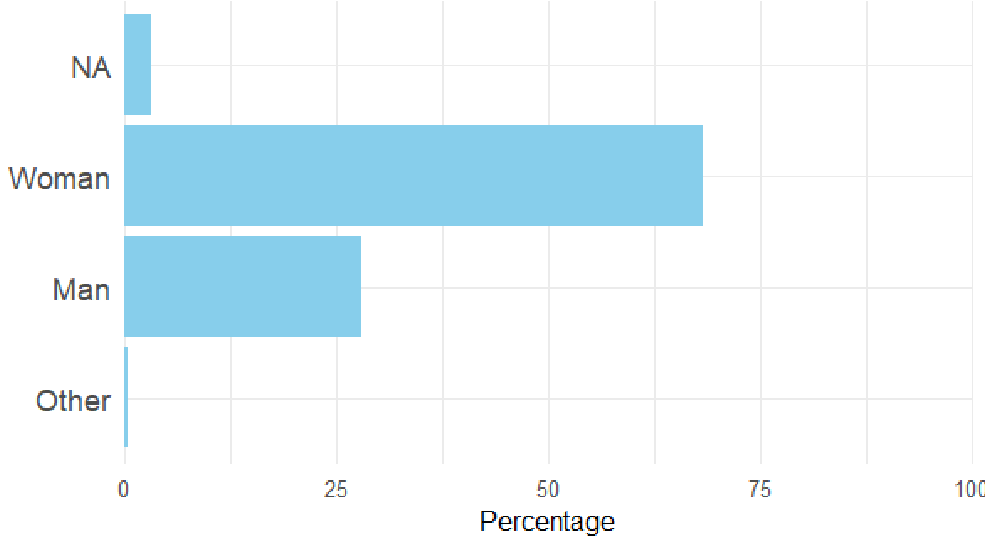
Religion

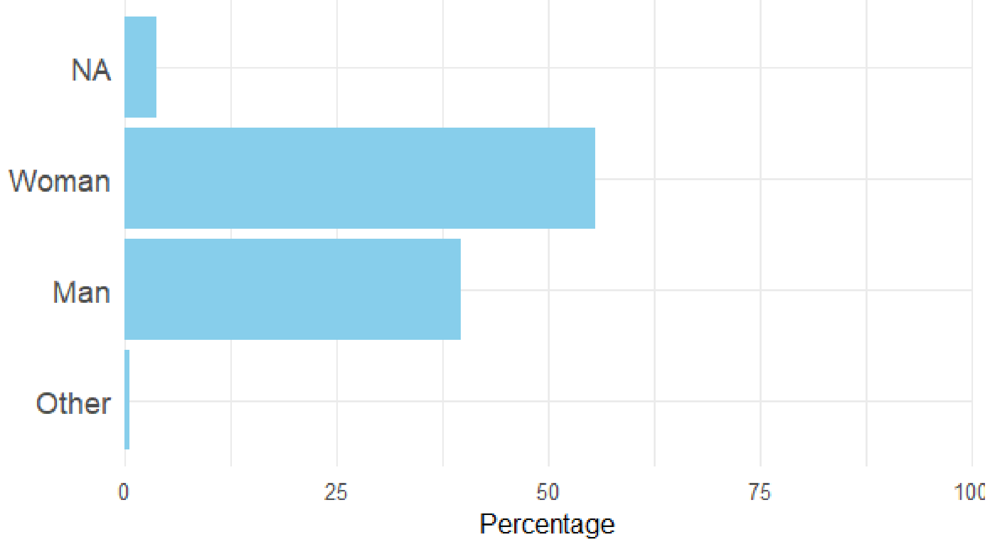

Religion according to census data and Our data
Christian
Atheism / No religion
Muslim
Not answered
Other religion
Hindu
Buddhist
Jewish
Sikh
0
25
50
75
100
Percent
Source
Manchester
England.and.Wales
Our.data

Disability


Disability according to census data and Our data
Not disabled under the Equality Act
Disabled under the Equality Act
0
25
50
75
100
Percent
Source
Manchester
England.and.Wales
Our.data

Gender

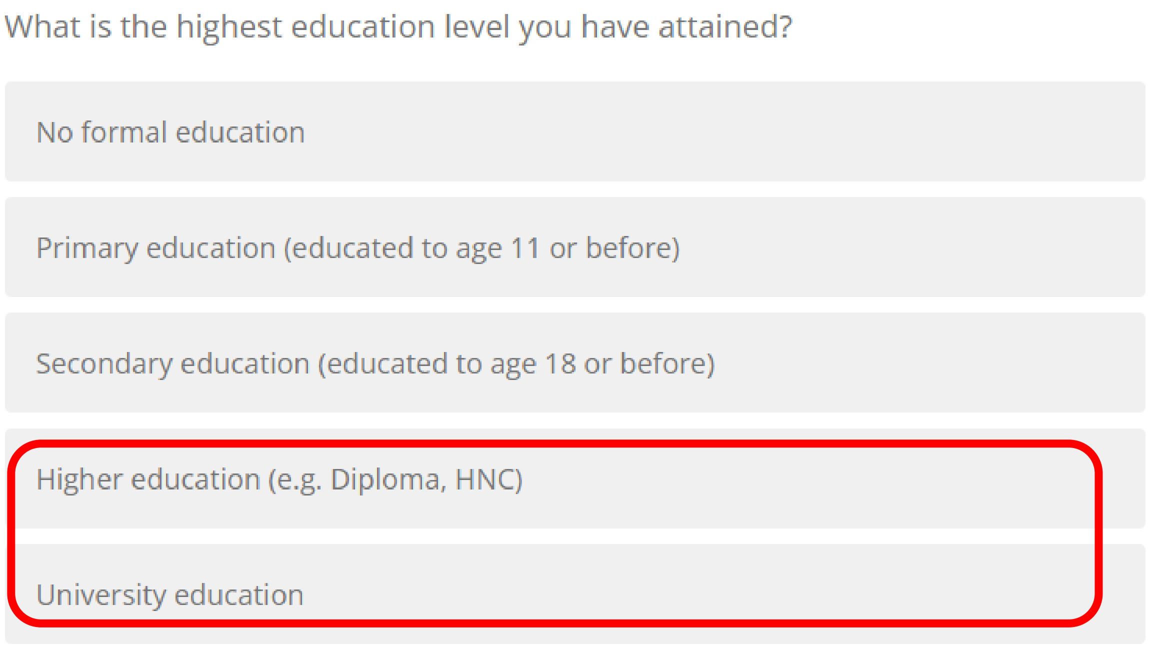



Excluding bambino_1 and bambino_2

Does your sex registered at birth match your gender?

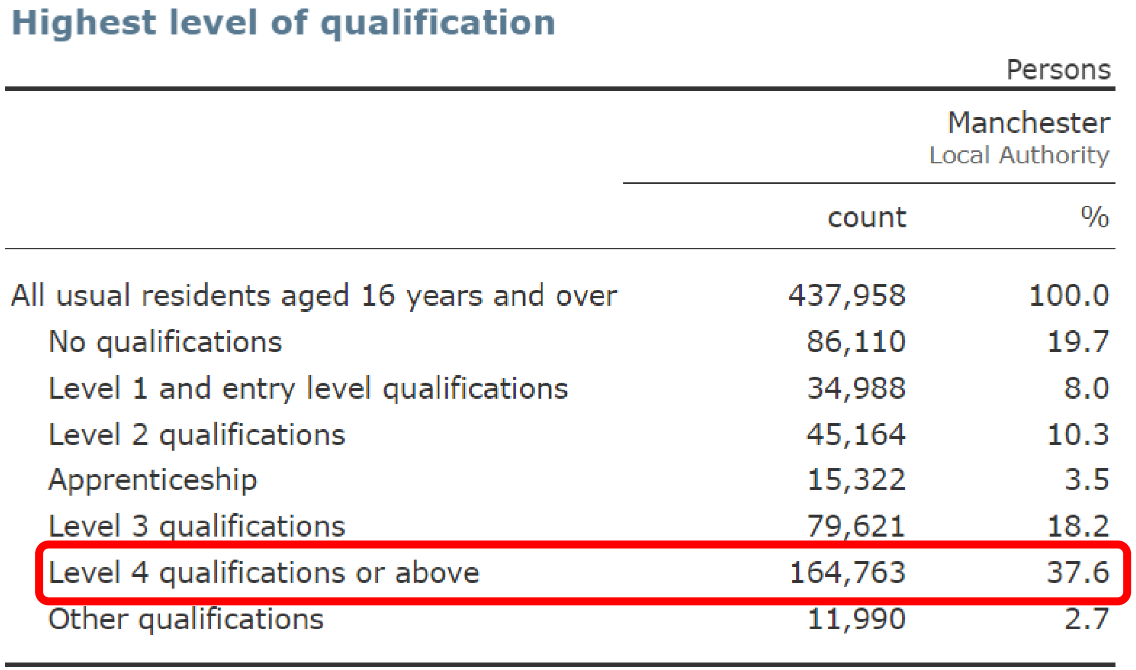
- 96% YES
- 4% No answer / prefer not to say

In V2 modified to: 'Do you identify as trans?' (2021 census data suggest this questions was poorly understood)



What is the highest education level you have attained?

- No formal education
- Primary education (educated to age 11 or before)
- Secondary education (educated to age 18 or before)
- Higher education (e.g. Diploma, HNC)
- University education

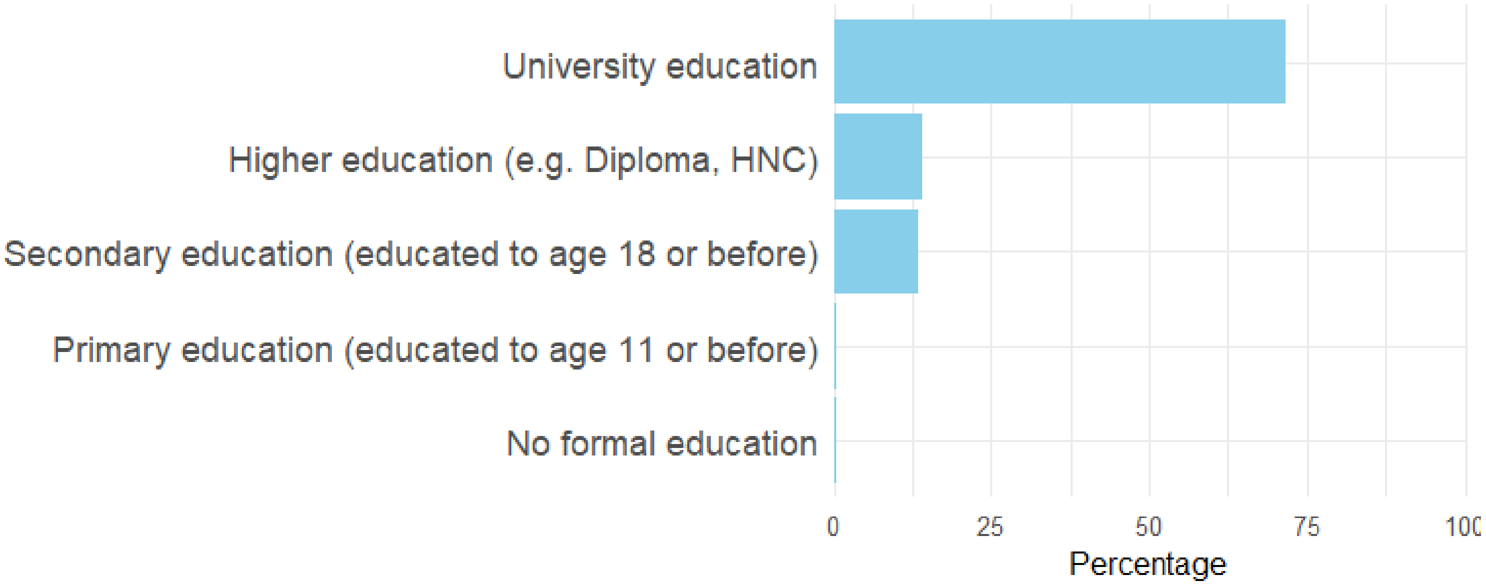


Highest level of qualification

Persons

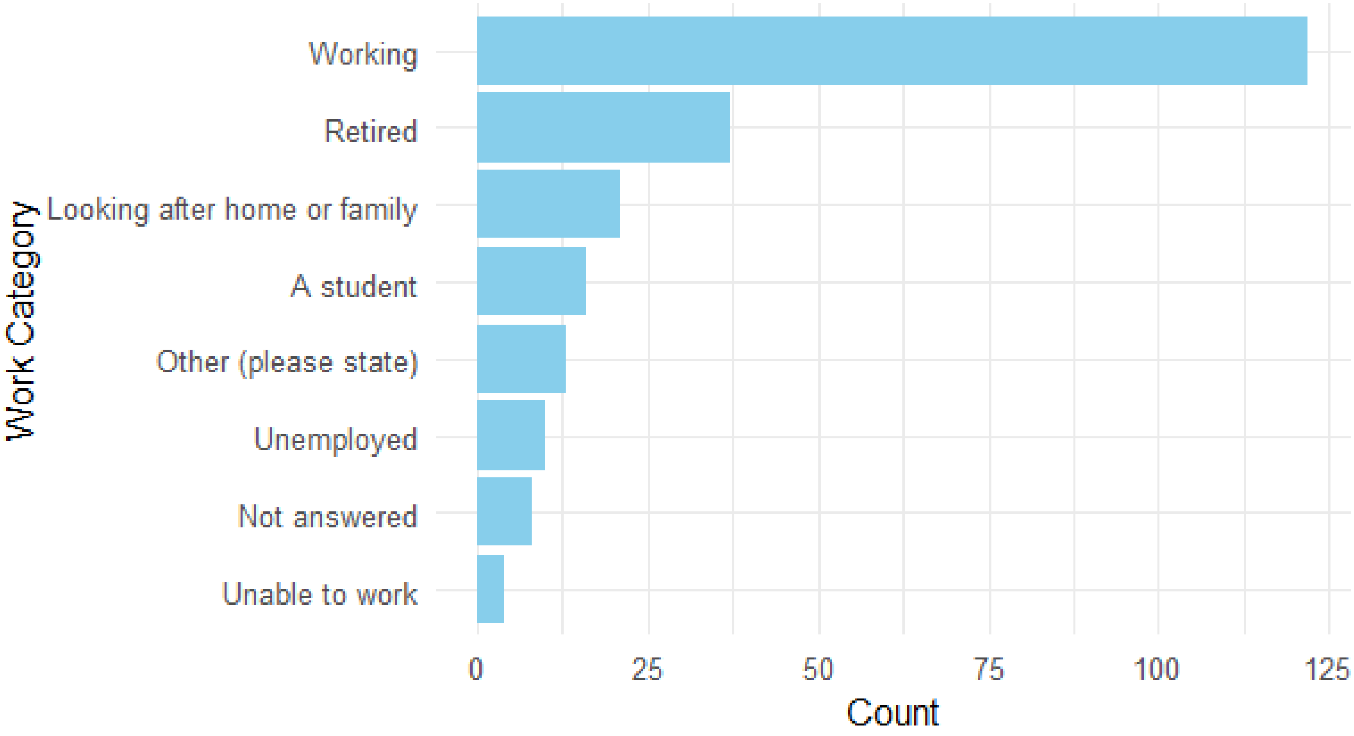
	Manchester Local Authority count	Manchester Local Authority %
All usual residents aged 16 years and over	437,958	100.0
No qualifications	86,110	19.7
Level 1 and entry level qualifications	34,988	8.0
Level 2 qualifications	45,164	10.3
Apprenticeship	15,322	3.5
Level 3 qualifications	79,621	18.2
Level 4 qualifications or above	164,763	37.6
Other qualifications	11,990	2.7

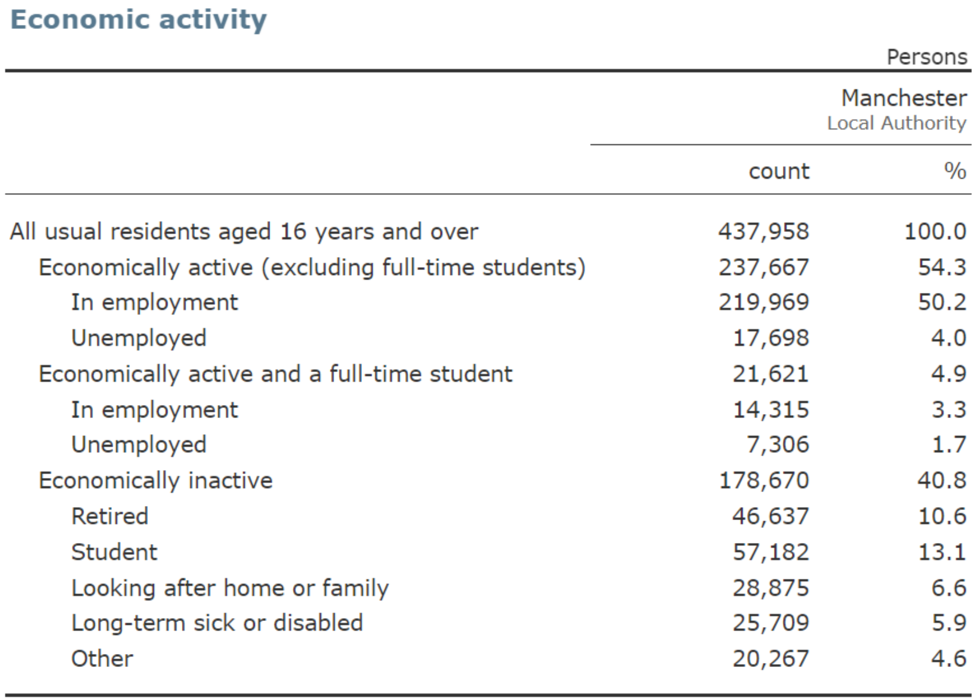
Education Levels in Our Data



- 38% vs 85% Level 4 qualifications or above

Working status ('tick all that apply')





Economic activity

Persons

	Manchester Local Authority	
	count	%
All usual residents aged 16 years and over	437,958	100.0
Economically active (excluding full-time students)	237,667	54.3
In employment	219,969	50.2
Unemployed	17,698	4.0
Economically active and a full-time student	21,621	4.9
In employment	14,315	3.3
Unemployed	7,306	1.7
Economically inactive	178,670	40.8
Retired	46,637	10.6
Student	57,182	13.1
Looking after home or family	28,875	6.6
Long-term sick or disabled	25,709	5.9
Other	20,267	4.6

Take-home messages and next steps

- Researchers are getting on board with the importance of collecting these data
  - It’s really easy
  - Everyone wants us to collect this data
  - It helps us better understand our participants and identify potential barriers to inclusion
- This matters…
  - Healthcare research must be representative of the communities affected
  - Research inclusion increasingly a condition of funding (e.g. NIHR)
- There is more work to do re the data analysis…
  - Adjusting datasets for inclusion criteria of individual studies (as a minimum)
  - How to understand and address impacts / biases of non-respondents? How to *prioritise* this data collection?
  - Work with the wider BRC to share best-practice
  - Could consider our priorities and adapt future questionnaires accordingly

Take-home messages and next steps

- Under-represented groups appear to include:
    - People with lower education
    - People from the Muslim community
    - Men
- There is work underway re reaching out to communities
    - Several researchers and PhD students in the team have been doing an excellent job of reaching out to communities
    - We plan to set up a hearing health inclusive research working group to address barriers
- What we can do now…
    - Consider whether our avenues for recruitment are biased towards more educated people and how to address that (e.g. advertising in community centres rather than a University campus)
    - Give adequate compensation to minimise barriers and consider wider possibilities and compensation, e.g. taxis, compensating travel *time*
    - Share what works

Thanks for listening. Thanks to the Inclusive Research Methods and IROB teams.

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