



# Overview of research project

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# The work included:

Evidence review	Studies and ethnicity recording by public bodies
Community participants	Focus group sessions with 41 African, Asian, Caribbean and minority ethnic people in Bristol, Manchester and South West England
Healthcare worker participants	46 clinical and non clinical workers from primary, secondary and community care. Combination of focus groups and individual interviews with participants from North West of England, Midlands, London, East of England, South West of England



# Findings from community participants

1. Ethnicity must be **self defined** but there was varying understanding of what ethnicity is.
2. The existing **ethnicity categories** are recognised but not appropriate for everyone.
3. Participants were generally happy to share their ethnicity with health services but, an **explanation** as to why ethnicity data is collected is rarely given, which can lead to caution (suspicion) or refusal to answer.
4. **Racial discrimination** was the **main risk** associated with providing ethnicity data.
5. Providing **adequate, easy to understand information** would help some people feel more confident to provide their ethnicity data.

# Understanding ethnicity

*'When we all in China we won't talk about ethnicity but since we migrant or move to England then they will ask what is our ethnicity'*

*'I worked in the health sector in Sri Lanka so I know about patients' data, how they collected, what, what they use, so I know that. But we never collected any ethnicity or anything'*

*'Traditions...usually it's your family upbringing and how you see yourself'.*

# Ethnic categories are not appropriate for everyone

- There was some confusion as to how ethnic categories was defined – nationality, skin colour
- Negative feelings were associated for those where there was no specific category, leading to ‘undervalue’ and ‘othered’.
- Ethnicity must be self defined
- Trust impacts on the willingness to provide ethnicity data

‘When you have your own boxes it almost feels like you are valued. When you are not having your own boxes, it means like you don’t care, you’re not even a ‘name’. You are nothing. You are ‘other’. ‘Other’ what?’

‘I suppose for me it depends on...what they’re using it for’

# The process

- Community participants were generally unaware of why ethnicity data is collected - *'it's a requirement' 'it's for stats'*.
- Lack of transparency contributed to distrust especially where health inequalities persist
- Ethnicity should be collected on initial contact rather than through all stages of the healthcare pathway
- To avoid repeatedly answering the question, community participants suggested a centralised system with all the data stored would be the most efficient option for health services.

*So, it's quite a cynical reason we've given all this data, but it isn't changing our outcomes yet'.*

*'They are asking the same question and every nurse or doctor knows me but every time they ask 'so ethnicity?'*

*'In Hong Kong, the whole health system has got a system, you know, computerised centralised system, so whenever a patient put in any information, is all put in this system'.*

# Risks to providing ethnicity data

- There is limited understanding of the association between ethnicity and health;
- Providing ethnicity data was associated with the potential risk of racial discrimination; and
- The security of data storage and access to data were key concerns.
- Address information needs

*'...we all know that when it comes to Black care in the NHS system, we're not given the proper care, we're not looked after the same.'*

*'I don't mention where I'm from because people have a really bad perception of Albanian people'*



# Findings from Healthcare worker participants

Key findings in relation to:

- Understanding ethnicity
- Ethnic categories\*
- Recording ethnicity data\*
- Challenges to collecting ethnicity \*
- What affects collecting data?
- Data systems
- Prioritising ethnicity recording
- Data governance \*



# Understanding ethnicity

- All agreed ethnicity must be self identified but there was no clear definition of ethnicity used by organisations.
- For some staff, there was a lack of clarity as to why ethnicity data is collected.
- Understanding the 'rationale' behind collecting the data was suggested would help with collecting it

*'And there's certainly nothing around how to collect that data, how to interact with patients in order to obtain that information that's done in a safe and kind of clear way for patients, that definitely isn't something that's provided at the moment'.*

*'I see it simply as how you would classify race'*

*Is it because of Covid and a lot of minority ethnic groups has been affected more by Covid? I'm not sure*

# How is ethnicity data used?

- To address health inequalities issues
- Assist with language support
- To meet targets such as Investment and Impact Fund incentive scheme
- Research to identify specific conditions e.g., diabetes
- Used to inform standards being developed across a primary care area to help practitioners do targeted work with specific communities

# Ethnic categories: issues

- There is wide variation in the data categories used to record ethnicity in health settings.
- The generic ethnic categories were deemed not specific enough to record some ethnicities.
- The use of arbitrary categories such as 'not specified', 'not asked', 'not stated' or 'not known' are not helpful to record ethnicity.
- Categories are not up to date or extensive enough

*'Sometimes they get mixed up between Arab and African between the African as a continent and between Arab as a race'.*

*'So, for example, when a patient has their ethnicity recorded as 'not known'. That it's an, it's basically an acceptable response to what the system wants.'*

# Recording ethnicity data

- Hardly any workers had received guidance, training or information on how to request and record ethnicity data
- Assumed data collected in primary care/on system is correct.
- All acknowledged ethnicity must be self identified but most healthcare worker participants were aware that assumptions had been made about ethnicity based on perceptions and visual appearance.

*'I don't think we've ever been given any guidance on ethnicity or religion really. We've never had like, a script of sorts to read out if anybody asks, and I'll probably be handy because at least Clerk's would have an understanding of why we're asking for it. Rather than just trying to make up something come spot, they'd have a proper understanding about say.'*

# Challenges to collecting ethnicity data

- Feelings of 'awkwardness' and lack of confidence when requesting ethnicity data from patients.
- Patients understanding of ethnicity was noted to affect the information they provided.
- The inability to provide adequate explanations as to why ethnicity data is being requested.
- Perceiving ethnicity only with race affected who the data was requested from.

*'So, I guess my observations of other people collecting ethnic data is around if they look physically different than they may ask. Whereas if they don't look physically different to the White British assumption, then they won't ask and they'll just record White British, I think it's up that sort of thing, likely.'*

*'If you translate the word ethnicity to Arabic, it's, it's, it tells something competently different. The people they get mixed up between ethnicity an nationality'*

*'It's normally, we say it's a government initiative that we have to ask these questions, because that's how it was explained to me.'*

# Data governance

- Proposal for mandatory recording of ethnicity but issue about data quality
- Overall, processes for correcting ethnicity that is already recorded were either not known, or inconsistent.
- There were some examples for auditing ethnicity data.
- There are opportunities for healthcare practitioners to address missing ethnicity data in their contact with patients.

*'Well, I personally, I would just put in what the patient says. So, I will change it and what they say. And for me, that's what I would do.'*

*So that's the local hospices electronic patient data, information data. So, when they get called to such patients, I have encouraged the team to often ask the patient or their relative how they will best describe the ethnicity'*

# Some current work to improve ethnicity recording

Patient Navigators

Ethnicity Champions working  
with Gypsy and Traveller  
communities

Developing resources and  
information sheets

Reviewing use of 'not known'  
category

Role play – association  
between ethnicity and health  
inequalities

Equality dashboard



# Overall Recommendations

1. Better explanation of why ethnicity data is being collected.
2. Develop better knowledge of links between ethnicity and health.
3. Ensure ethnic categories reflect the current communities.
4. Develop consistency in approach for recording ethnicity.
5. A role for communities to contribute to how ethnicity is defined and categorised.