

Improving the recording of ethnicity in health datasets

Exploring the views of
community respondents and
the healthcare workforce

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Understanding Patient Data

Understanding Patient Data is a programme of work based at the Wellcome Trust. The aim is to make the way patient data is used more visible, understandable, and trustworthy, for patients, the public and health professionals. More information is available at <https://understandingpatientdata.org.uk>

Other work of interest is that of Liberating Knowledge which explored patient data for Black and Asian communities.

Executive Summary

Incomplete or inaccurate recording of ethnicity will undermine attempts to address health inequalities and improve access, experience and outcomes for Black, Asian and minority ethnic communities.

The Race Equality Foundation and the Office for National Statistics were commissioned by the Wellcome Trust to look at different aspects of the recording of ethnicity in healthcare. The Foundation was tasked with gaining better insight into the collection of ethnicity data by and for healthcare. We interviewed people from a range of communities across England, as well as healthcare workers from different areas and settings to understand both sides of the process of collecting ethnicity data.

We found a number of examples of good practice in the recording of ethnicity. However, we also identified significant problems that undermined the value of the ethnicity data recorded. A number of these problems were apparent in responses from the community participants as well as from healthcare workers, for example, understanding why ethnicity data was being asked for.

These issues must be addressed urgently so that the data can be used to better effect, but also because it is likely to improve the willingness of communities to provide this information.

Key findings: Community participants

1. The understanding of ethnicity varied from person to person, including differing opinions on whether skin colour and religion are included in a person's ethnicity.
2. An explanation as to why ethnicity data is collected is rarely given, which can lead to caution (suspicion) or refusal to answer.
3. The link between ethnicity and health conditions and outcomes is not well-known or understood.
4. Ethnicity categories are not appropriate for everyone and can cause confusion, leaving some people feeling undervalued, underrepresented and unsure of what to select.
5. Under no circumstances was it deemed acceptable for healthcare staff to fill out a person's ethnicity themselves or change what was written.
6. Racial discrimination was the main risk associated with providing ethnicity data.
7. Some participants understood and were willing to provide their ethnicity data. But some people said they would feel more confident giving ethnicity data if they were provided with adequate, easy to understand information and that health services engaged with them in their community.
5. There was inconsistency with the ethnicity categories used in different healthcare settings. But participants felt the categories were overall reflective of their local populations.
6. Categories 'unknown', 'not specified', 'not given' or 'asked but not given' were recorded on patient records. This was marked as complete, despite not giving any clear indication of ethnicity.
7. Most participants tasked with collecting ethnicity data did not know why they were collecting the data and how it would be used. This ultimately impacted any explanations they would give to patients.
8. There was the potential for discrimination in ethnicity data collection and it was not clear of any safeguards in place.
9. All participants agreed that ethnicity recording was of high priority but competing priorities and resources affected the commitment to this.
10. There was a lack of clarity about procedures to check the accuracy, consistency, and auditing of ethnicity data. But some organisations were addressing the challenges outlined which led to more consistent and accurate recording of ethnicity data.

Key findings: Healthcare workforce participants

1. It was agreed that ethnicity is important to collect and that this should be self-reported by patients.
2. All participants agreed that ethnicity must be self-identified but examples were given where ethnicity was assumed based on race or visual appearance.
3. Challenges to requesting ethnicity data were dealt with by some participants developing a personalised approach.
4. There was no standardised definition of ethnicity used to request ethnicity data.
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.

Overall recommendations

Introduction

Debates and discussions around the recording of ethnicity has revealed that there are issues concerning the appropriateness of the categories used to describe different communities, as well as the consistency and quality of the data that is recorded. Ethnicity data was used to demonstrate the disproportionate impact of Covid-19 on Black, Asian and minority ethnic communities. Yet this analysis and recent investigations have identified poor quality in how ethnicity data is recorded across health and care settings. This raises a question about the reliability and use of ethnicity data for the analysis of health conditions and health inequalities. The Race Equality Foundation was commissioned by the Wellcome Trust to undertake research to gain better insight into the collection of ethnicity data in healthcare settings.

Methodology

A literature review was undertaken of studies of ethnic identity and its recording by public bodies. The review informed the engagement work undertaken with Black, Asian and minority ethnic communities and healthcare workers. The discussions for the community participants centred around their understanding of the meaning and purpose of the ethnic classifications used, and their experience of being asked for or providing information about their ethnic group through different methods and within different settings. Discussion for healthcare workers centred on exploring how they understand the meaning and purpose of the ethnic classifications used; and the issues faced when collecting and recording ethnic. Both sets of participants helped to develop solutions and recommendations to improve the quality and quantity of ethnic data recording. The focus group guide and interview topic guide are in the appendix.

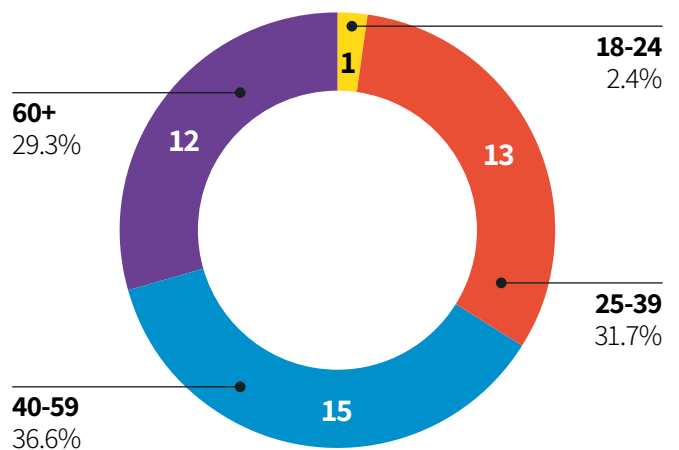
Engagement with community participants

Participants from Black, Asian and minority ethnic communities were recruited via voluntary

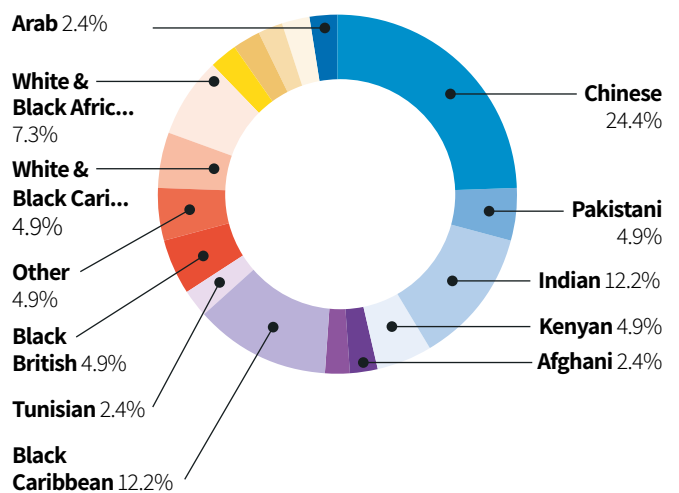
and community sector organisations in three geographical areas: Bristol and the South West of England, Manchester and London. Participants were required to take part in three focus group sessions. In each area, sessions took place with a community language interpreter and a separate session for English speaking community participants. There were six focus group sessions per area, giving an overall total of 18 sessions. In total there were 41 community participants who took part in the research.

We heard from people across a range of ages and ethnicities, both demonstrated in the charts below:

Community participants: Age



Community participants: Ethnicity



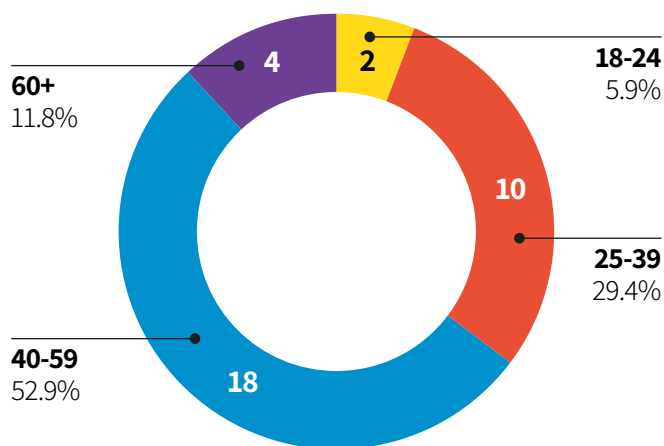
The purpose of having three sessions with each group was to allow time to develop the conversation, explore people's thoughts and feelings in more depth and to use each conversation to build on the next. The discussion guide for each focus group included participatory activities and hypothetical situations for community participants to engage with to explore different aspects that might impact on ethnicity classification and recording.

Engagement with healthcare workers

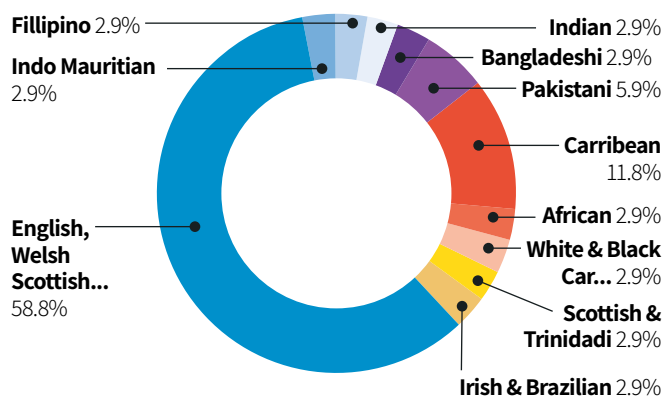
The healthcare workers were invited to participate in focus group sessions or take part in one-to-one interviews. We were particularly interested in those who were tasked with collecting or recording ethnicity data or were responsible for analysis and quality assurance. Healthcare worker participants were recruited from the North West of England, Midlands, London, East of England and South West of England. 46 healthcare workers participated from primary, secondary and community health settings, including non-clinical staff such as receptionists, administrative staff, Practice Managers, Performance and Quality Manager, and clinical staff ranging from Endocrinology Gypsy, Roma, Traveller Specialist Practitioner and Clinical Nurse Manager, amongst others.

Healthcare worker participants varied in age from between 18 to 60+, and whilst the majority (58.8%) were from the UK, we heard from people across a range of ethnicities, including Filipino, Caribbean and Indo-Mauritian. See tables below for a more detailed breakdown of age and ethnicity:

Healthcare worker participants: Age



Healthcare worker participants: Ethnicity



Focus groups and interviews with healthcare worker participants were held following engagement with community participants, to ensure learning could be used, where relevant, to inform the conversations and provide examples of experiences community participants shared.

Further information on participants is in the appendix.

Findings from the engagement with community participants

The research aimed to explore how individuals from Black, Asian and minority ethnic communities are asked about their ethnicity and how this in turn is recorded.

Key findings

1. Understanding of ethnicity varied from person to person including differing opinions on whether skin colour and religion are included in a person's ethnicity.
2. An explanation as to why ethnicity data is collected is rarely given, which can lead to caution (suspicion) or refusal to answer.
3. The link between ethnicity and health conditions and outcomes is not well-known or understood.
4. Ethnicity categories are not appropriate for everyone and can cause confusion, leaving people feeling undervalued, underrepresented and unsure of what to select (in part due to the categories not being consistent i.e. based on continent, skin colour, nationality).
5. Under no circumstances was it deemed acceptable for staff to fill out a person's ethnicity themselves or change what was written.
6. The main risk associated with giving ethnicity data was said to be racial discrimination.
7. People would feel more confident giving ethnicity data if they were provided with adequate, easy to understand information and health services engaged with them in their community.

The problem with 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 mean, in Hong Kong, there is no ethnicity, you know, they won't ask you for your 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.'

Ethnicity meant slightly different things to different people. Some of the words used to describe ethnicity included language, heritage, identity, country of origin, cultural background, skin colour, lifestyle and religion. For example:

'I think ethnicity is where you're from, where your parents are from, where you're brought up. Anywhere you feel that belongs to you really, where you feel home.'

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

The problem with current ethnic categories

There were several issues identified about the use of current ethnic categories.

- Nationality plays a role in understanding ethnicity.
- Ethnicity is understood differently amongst multiple generations of minority ethnic communities.
- External factors affect how ethnicity evolves and is understood.
- How comfortable people are providing the information will affect the information that they give.
- Trust impacts on the willingness to provide ethnicity data.

Ethnicity categories vary according to which form people fill out, with some offering more choices than others. The categories available were described as *'a bit clumsy'*. There was some confusion about the different types of categories, for example, some categories are based on a country, and others based on skin colour and a continent. For some people, this made choosing a category less clear:

'...so for me is it's very hard, you know, and if you've got a British passport, you're going to say that you're English, but yet they're defining you by your colour.'

The idea that skin colour is tied into ethnicity for particular groups was not accepted by all:

'...recently I just put British. Not Black British, just British. Because mentioning colour, there's no meaning to me you know.'

This sentiment was shared by other community participants, with one person wanting to make a clear distinction between ethnicity based on geographical place rather than race:

'I think if we need the ethnicity, so I prefer to look at it as geographic place. For example, the Middle East includes Turkey, Syria, Lebanon, Jordan, many different places. For example, China or we can put mixed group and leave open space to describe themselves. So for example,

we are going to have British or African, we don't need White and Black. We need just British and African, American and a country, not a colour. So for example, 'Arab' we can use Middle East and Middle East take a big group and describe.'

Another person who had lived in the UK for many 'decades' had noted the changing terminology used to describe their ethnicity commenting:

'I think Caribbean or Black British has no meaning to me anymore. Not because I'm not proud of it, is just why these terms were used. I was called coloured when I was young and now I'm called Black British. So, it's changed over time, and due to history being distorted as it is, I don't think it really has meaning, you know, some people it will, but to me it has no meaning anymore. I'm British. The colour before it has no meaning to me, you know, makes no difference.'

In contrast, someone else said:

'...for me I just tick Black, Black African Caribbean I'm never bothered just as long as it's the colour of my skin. I just put Black.'

Those who were easily able to relate to a category were generally satisfied with the categories available, for example, those from China or Bangladesh. However, there was less satisfaction for those who did not have the correct category to accurately represent themselves, for example, those from Bulgaria or Afghanistan. Reportedly having the right box to tick almost indicates a person's value, so when someone has to tick 'Other' they don't feel like a valued member of society: *'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?'*

Some community participants were very clear on the category they wanted to tick and have been disappointed in the past when it wasn't available:

'I put myself down as Black British, I'm specific I don't want to be classed as Black Caribbean or Black African because I just don't know it, I

know that that's meant to be my culture and I'm black. My grandparents are, but I'm born here, I'm westernised. I like everything English. Yeah, I just don't feel ... I'm Black British, not Black African. Yeah, do you know what I mean, I just think I'm British. I know I'm black. And I get my family are black and I get where I'm coming from. But yeah, me personally. My parents were born here in England. And I was born in England. And I'm a British citizen.'

Some community participants wanted to see Hong Kong as an option, as they said their passports say Hong Kong and their culture and traditions are specific to there. Through an interpreter one community participant said:

'she's grown up in Hong Kong and she think that it's a bit different to China, so she would describe herself as Hong Kong, not from Chinese, not from China, because of the location is quite special. We used to have our own culture or own background. So, she would describe herself from Hong Kong but not from China.'

They went on to say:

'...you can choose China, but not Hong Kong and then there was one time she can choose from Hong Kong, but now it's changed again. So, it's like, it's always changing. She's not, she doesn't know why, but it's always changing. And then she feel like, that is a problem. She wants to express that she's from Hong Kong, but she's not, not able to.'

The role of nationality in understanding ethnicity

Some people felt that it would be viewed more favourably if they added the British option to their ethnicity. This was despite the fact that they felt their ethnicity had not necessarily changed. One community participant said:

'...why does that British hold more than just a normal, you know what I said, when I was at the age of six, I came to this country. So, if you asked me to fill that form, and I've just say Pakistani and if you ask me at 10 I'd say Pakistani. I'm a British Pakistani now. Why is that British got more weight than just Pakistani?'

With someone else saying:

'In fact, it feels like why does it have to be defined? Is there right definition for it?... I feel like why would you have to state you're British Pakistani, why can't you just be a Pakistani?'

Younger generations who were born in England were more connected to the ethnic categories which had British in, such as Black British or Pakistani British. Older generations who had moved to England did not see the need for British and in some instances felt it was taking away from their ethnicity, which is demonstrated in the comment above.

It was clear that not having a category that accurately described a person was associated with negative feelings, which some described as not feeling valued and others said it was a problem. Most community participants agreed that a write in box where people could self-define was important. Community participants commented through the interpreter:

'They prefer open questions like you know, they decide you know what specific like 'I'm from Shanghai or I'm from China', they prefer to give the give the right to make the decision how to answer that. Not specific 'are you from China'. Or you know, 'are you from Japan' or something like that, not, not like this. They prefer they can record their you know, ethnicity from their decision.'

The problem with capturing multigenerational understandings of ethnicity

Community participants said ethnicity was becoming more confusing for people's children and grandchildren who may have parents with different ethnicities, but they themselves have been brought up in England. Or the parents share an ethnicity, but the children have never been to their parents' country of origin and have not experienced the cultures and traditions from that place. For example, someone commented:

'So that last group that were my kids, you know, my husband's from here, and I'm from Pakistan but we don't really go Pakistan, and it's changing. My kids wouldn't even say that,

you know, they've never, we don't ever use Pakistani much. It's more the religious side, you're Muslim,' with someone else saying 'only my son has a partner from Italy and she is half Italian and half Arabic and my grandson, I don't know where I need to tick because it's mix it from White, European, Italian, Arabic. He has many bloods.'

Suggesting that this demonstrated the difficulty of capturing their ethnicity in one box.

An evolving definition of ethnicity

Some community participants found their ethnicity changed over time due to external factors such as terminology changing or because they themselves changed the option they chose. Although when asked what ethnicity means one person explicitly stated:

'It's something that we can't change.'

Some community participants raised the issue of the options and terminology changing overtime and how that relates to them and their own identity:

'...it's true what you're saying about it being changed over the years...your identity gets changed and you're like what? Like today I'm mixed race, and oh tomorrow I'm mixed heritage. We just wake up and we're Black every day.'

This highlights the complexity of ongoing external changes of how someone is referred to, in contrast to their day-to-day experience as someone who is viewed as Black. With Mixed categories only being introduced by the Office for National Statistics in 2001, the person went on to say:

'Well, because now it's on there, it is mixed. But my problem with this term is that it went from half caste to dual heritage to you know like when is it gonna stop? Stop putting things on me, I'm just mixed between two races I'm happy there. Like bi-racial sounds like I'm a science experiment or something I don't know. Like how far can it go from half-caste which is not correct to now they're just making up all these words. They'll say well, that's what you should refer to yourself as. Says who?'

Some complexities were discussed around whether a person's ethnicity changes once they gain citizenship somewhere. For example,

changing from Pakistani to British Pakistani once a person has their citizenship, someone said:

'...on paper you're British if you're born in London, but your ethnicity is somewhere else,'

Another participant said:

'...what are you? British Pakistani or a Pakistani? And then just because you've got the passport? Or, you know...if they want to just know ethnicity whether you're Pakistani or something else?...So again, this question is, why are they any different? Why does I have to tick British Pakistani, whereas my uncle might just think Pakistani, you know.'

Other reasons given for ethnicity changing over time included it being situation-dependent, for example if a person was ill or short of time, they may choose whichever is easiest:

'Depends, you're in a hurry, or ill or something put Other, Black Caribbean, Black African, Middle East, whatever. Mixed race, whatever. I just look at the last thing, 'Other', I put that one.'

Another reason was through marriage, it was said that some women from South Asia may 'follow the husband' if they have a different ethnicity. Someone explained a situation where their son who is British-born Chinese says they are from Singapore to avoid racism and discrimination:

'...exactly, racism discrimination, and that's why he said you know 'no I'm from Singapore I'm not from China' yeah.'

In our discussion we asked community participants to consider whether it was acceptable for someone to change the ethnicity they stated. There was general agreement that it was not acceptable under any circumstances for a healthcare professional to change what someone had written their ethnicity as. Any blanks/unfilled boxes should be left as blank, even if healthcare workers believe they can accurately describe a person's ethnicity. Many people stated that it is up to an individual to determine their ethnicity:

'Thing is...my point, you know, because ethnicity, I am going to give it to you, you can't determine my ethnicity. I'm going to say who I am, you know.'

Community participants felt it was ‘unfair’ and no one *‘has the right to tell you what country you should be able to tick.’*

Individuals’ comfort in providing ethnicity data

How comfortable people felt giving their ethnicity data varied. This is demonstrated in this one comment alone:

‘So I tend to just do it kind of automatically, almost I don’t really pay a lot of attention to why it’s asking what it’s asking, but I have colleagues, friends that either leave those blank or choose something completely different to what they are because they don’t see the point in it.’

Some have become so used to providing their ethnicity, they just fill it out automatically and don’t think about it, as a few people commented *‘tick, tick, tick’*. Others said that because it was being asked in health settings, they had no problem providing the information. One community participant commented:

‘Yeah, we can because this is to the hospital and yeah, it really matters to them. They [patients] will provide everything that you ask.’

This was particularly true for many of the Chinese community participants, with one saying ‘It’s simple, easy’ in reference to how comfortable they felt giving their ethnicity.

For one community participant their feelings on giving their ethnicity had changed over time, going from feeling quite negative about being asked to answering with no hesitation:

‘You know, we are human, we are equal. Then on that time, I was very crazy about these questions. Now, I told you before, I’m easy, I think it’s that okay? Fine. They just want to know, I don’t know why they want to know, but just they want to know, just Tick tick tick.’

Other community participants remained cautious about providing this information, with one person saying: *‘I suppose for me it depends on... what they’re using it for’*, suggesting that there may be a lack of trust, which is demonstrated in this comment:

‘I don’t trust them, the medical authorities, doctors have become traders.’

Other community participants did not see the need to group people by ethnicity and felt it was unnecessary to collect this data, with someone stating:

‘...we are all humans’ and another saying: ‘I feel there is no need to describe the people as them ethnicity or them colour or them religion.’

It was clear that some felt uncomfortable providing their ethnicity and preferred not to say or in one instance:

‘I put alien on there and they couldn’t say anything, because that’s how I relate to myself as alien.’

Another participant commented:

‘...to be honest, I come for this meeting to ask why we still include every form in UK about ethnicity and where we are originally come from, and I feel this is part of – I didn’t understand, I when I fill any form I prefer not saying.’

The role of trust

The need for transparency was made clear by the lack of trust some people had in why ethnicity data was being collected and how it was being used. Community participants suggested the more information people were provided with, the more willing they would be to share their details. This was teamed with the need to be held accountable; if people are giving their data, they want to see direct improvement in the services they receive:

‘I think it’s always good to be transparent and people are more willing to give, give up their information when there’s transparency, and also when... there’s change happening because of that data, you’re not just taking that data and going off and saying, oh, yeah, we’ve ticked X amount of boxes, but rather actually providing with the service that I need, because there is a need for that service.’

When asked how people felt about providing ethnicity data, one community participant spoke about some outreach work which was taking place which had been effective in engaging South Asian women in establishing healthy lifestyles. They said often:

‘...they [health practitioners] want to know more, but they’re not coming into the communities. So,

it's like, why don't you come in and ask, you know, build that relationship, that trust relationship first, and people will be happy to share.'

With reference to sharing information they went on to say:

'...sometimes it's a fear of not knowing what you're giving your answers or who you're giving?'

This outreach work positively impacted on the health literacy of the women increasing their confidence and ability to engage with the health sector. They went on to say:

'...once we know, it's a good purpose, I think we're happy to, a lot of ladies are happy to give it [ethnicity] now.'

Community participants suggested people would feel more comfortable providing ethnicity data if

they were provided with more information around why it is needed and what will be done with it. They would be more willing to provide information having a better understanding of this. Chinese and Black community participants also suggested that a more diverse workforce would help put people at ease, with one person commenting:

'..rather than you know you translate all the forms into different languages better do, to, you know, increase the diversity in the staff it will be better...that's Cantonese I can talk to her directly...It might be better feeling and a bit comfort...you know the initial form filling.'

Interestingly, during engagement work with healthcare workers we heard about an approach using patient navigators and the health inequality worker, where their community language was used as an asset contributing to accurate form completion.

Process

The collection of ethnicity data was discussed at length. Some key areas were raised by community participants around who is collecting the data, why they are collecting it and when.

These discussions raised:

- Collection of ethnicity data for health purposes was deemed acceptable;
- Community participants were generally unaware of why ethnicity data is collected;
- Repeated requests for ethnicity data were not deemed necessary; and
- Some ways of collecting or updating ethnicity data was more acceptable than others.

Who is collecting ethnicity data?

Many people recalled the last time they were asked for their ethnicity. Examples included a job application, for a volunteering role, forms for their children at school and GP surgery. Most people felt more comfortable with healthcare professionals collecting ethnicity data, although some people were sceptical of the need for areas such as dentistry to collect it. One person commented:

'I had an emergency dentist appointment downtown, I had to get my tooth taken out and I had to fill out one of them forms that say that I'm Black whatever, which I don't understand because it's a teeth. So, whether I'm White, Black, Asian or whatever, we've all got the same teeth. What are my teeth Black? Eighth Caribbean? I was so confused.'

Interestingly, many felt less comfortable with ethnicity data being collected by other professionals, for example from government departments, employers and schools:

'But in school or education I, I feel there is not necessary.'

Community participants felt that whoever was collecting the data, whether a receptionist in a GP surgery or healthcare professional in hospital, there should be the option of an interpreter or translated materials to aid understanding.

Why ethnicity data is collected

It was consistently stated that people were not informed of why ethnicity data was being collected. Most people had never been provided with an explanation as to why health settings were collecting it and what they were using it for. In some instances, they had been told *'it's a requirement' and others 'for stats'*. One person commented:

'They never told me about these things. They just, oh you have to fill this form is very necessary. You have to, otherwise you can't come in, especially when you go to the hospital. You have to fill the, fill the form, otherwise, you're not allowed to attend appointment' and another said 'I don't know why they're asking. It does not feel good.'

The lack of explanation led to people not feeling clear about why they were being asked and how to answer accurately. For example, one person described living in many countries which has influenced their ethnicity:

'I'm from Arab country, but I grew up in many different places before I arrived here, so around five countries before I settle down in UK. So, each country, make my personality and make me changing myself. It's not just my colour, my religion, my way to live. So, everything changing by time. So, I just wondering why, why the, here in UK still including that ethnicity in the form.' When asked if they had been asked for their ethnicity in any other countries they said *'just one place, I don't want to say, but yes, just one place before UK, but it was research... it's not as here, every single form. For example, if you fill the GP form, if you read the college form, if you fill any form, they ask you. But I fill it one time in around 10 years ago, in one country, where I used to live, but it's for research... So they want to know, how many people living in this city from different country.'*

In relation to statistics being given as a reason for collection one person commented:

'...people have certain statistics and research obviously important because, you know, we get all this media hype about the reality of different outcomes for different ethnic groups...people wouldn't know only by our lived experience and what we tell each other, how we've been treated through pregnancy, or childbirth, and

all of that but the sad thing is, we can't see that that changes anything. So, it's quite a cynical reason we've given all this data, but it isn't changing our outcomes yet.'

Some people had an idea of why ethnicity data was being collected, with comments such as:

'...there is lots of question about ethnicity in UK, but sometimes I can understand because, for example, NHS, maybe should know our ethnicity because they need to give rights service, there's illness, about every ethnic group, there's different health problem or something' and 'the major reason they ask that question is because there are some sickness that is specialised to some ethnic group. So, they will need the data so that they can use to treat the patient.'

However, some people were cautious about giving the information because of the lack of an explanation as to why ethnicity data is being collected; one noted:

'...people will take more responsibility if they do that with understanding, you know, why we are doing this.'

The lack of transparency contributed to a distrust from some community participants who questioned what was being done with the data, especially as inequalities for Black, Asian and minority ethnic groups persist within health services.

Many community participants said an explanation around why ethnicity data was being collected and its relation to health would resolve some of the unanswered questions and result in people feeling more willing to share information. It was suggested that the explanation should be in plain English, easy to understand with the aid of pictures and be translated into community languages. People said it would be useful to see posters or leaflets in GP surgeries to look at whilst they are waiting.

To go alongside an explanation for patients, training for healthcare and administrative staff to better understand ethnicity, data collection methods and the reasons for collecting it was recommended. It was also suggested, to ensure people understood the importance of health services having ethnicity data, that healthcare professionals go into community spaces:

'I think healthcare practitioners need to come into the community and educate the community of like the really importance of the information.'

Others suggested going to the Mosque, to speak to people to share information and answer questions.

Where should ethnicity data be collected?

As mentioned above, people felt more comfortable providing ethnicity data to health services than other services, although asking for ethnicity data was not seen as acceptable throughout all stages of the healthcare pathway. For example, many people agreed that asking someone when they are in an ambulance on their way to hospital was not appropriate, with one person commenting:

'...that needs to be done earlier, you know, not done when the patient is going to the hospital, asking ethnicity when he's sick, that doesn't mean anything.'

It was most appropriate to ask during initial contact with health services, through GP registration. The check-in screens in GP surgeries were a good opportunity for people to check their ethnicity is correct.

One person, who has to go to the hospital frequently said:

'...they are asking the same question and every nurse or doctor knows me but every time they ask 'so ethnicity?', and I'm thinking I filled this last week. So, I would really like to know why they have to keep asking me the same question in the same place, not different places, and I never get the right answer, like I ask why you can't use the old form? 'Oh we can't use the old form''

As indicated here, some people felt it was unnecessary to check ethnicity every time someone had contact with health services, particularly if they have regular contact with the same healthcare professionals in the same places.

Data management

People had contrasting views on the best ways to ensure ethnicity data was complete and accurate.

Some community participants thought regular audits would be useful. This could be done in the form of a letter, text or call, although some said they may not trust texts with links they have to click on. It was said *'they will ignore it'* for those who do not understand English. One person had received a letter:

'I had something from the GP like a few years ago just to say like they were collecting everyone's ethnicity...they needed to fill in like update everyone's ethnicity.'

Some thought it was the responsibility of all healthcare professionals to keep records updated and complete, by asking patients frequently. Others said the person themselves has a responsibility to make sure their records are correct; they could do this by calling their GP or having access to their own records. It was recognised that not everyone has access to a computer or is computer literate so there would have to be multiple ways of doing so. Another person suggested having a dedicated role within GP surgeries for someone to ensure complete data sets for patients. A number of people said that having all a person's data including their ethnicity connected to their NHS number would avoid people having to answer questions often and healthcare professionals having to ask often. With appropriate data sharing agreements in place, this information could be accessible to different health departments.

Community participants recommended a centralised system where all data is stored and managed as the most efficient option for health services. One community participant recalled their own experience of working in a hospital in Hong Kong:

'In Hong Kong, the whole health system has got a system, you know, computerised centralised system, so whenever a patient put in an information is all put in this system'. It was said that collecting ethnicity data should be a standardised process across all health settings to reduce variation and improve consistency, including the training people receive. Someone commented 'I think it should be a standardised, you know, awareness thing that that goes out across the practices. So, it's not just one person does it this way, and another one does it another way, it should be a standardised procedure for the NHS.'

Ethnicity and healthcare

In exploring the links between the recording of ethnicity and people's experience of healthcare, several points emerged:

- There is limited understanding of the association between ethnicity and health;
- Family heritage is an important consideration in self-identifying ethnicity;
- 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.

Not everyone was aware how ethnicity links to health and why. Some community participants did not know that ethnicity can be connected to health conditions and outcomes and were curious to understand more. Whilst others did not believe that ethnicity influenced health, one person said:

'I think doesn't make any matter or changing. So, every person and his health and his case different from the other person... I didn't believe that colour or the background affecting for the health, for example, the, the Black as you say, the Black people in more affect for from COVID than the White one. I didn't believe that. But I will go with you to say this question in the form didn't make any matter, because every single person has his ability to divide disease, or his ability to carry on this disease. So I don't, I'm not agree with that. So, if, for example, I'm an Arab group, and if became, if I became British, changing my identity to be British, this is make a huge difference in my folder in the hospital. So that means I'm not affected from disease. Do you get what I mean?'

In contrast, there were people across the focus groups who demonstrated an understanding of the connection between ethnicity and health. Some community participants were aware of specific conditions which affect their own ethnic group as well as others, and how this connected to the care people receive. For example:

'...things like conditions, I think, again, through pregnancy they'll ask you 'we need to check for sickle cell' or this that and the other because you have this ethnic group.'

Diabetes and high blood pressure were raised as conditions connected to Black African, Caribbean and South Asian groups. Other people said ethnicity data may be used to determine medication or to produce data such as life expectancy.

One community participant who had some understanding of why ethnicity is important had questioned whether healthcare staff were providing adequately tailored health care for Black patients, saying:

'Remember, we can't have the same doses. So how are you making your things fit us, and fit people of colour? Because it doesn't, not one brush doesn't paint all or fit all, you know, one suit doesn't suit all, but yet, they will do that and like I said, you were a minority it is minor deal with whatever, you know.'

Another community participant was starting to question the ethnic categories in relation to health conditions, they said:

'...do you know with them being British and not British, does that affect, or is there a different category for them to, when it comes to data collection for health issues or problems, like I just feel like, why is that an importance...are you British Pakistani or are you Pakistani?'

This community participant was trying to understand what influence ethnicity would have, in relation to health conditions, if a person chose the category with British following their ethnicity. They went on to say:

'...for health, why does it have to be British Pakistani?... Are there two sections to say British Pakistanis will have these health issues and Pakistanis will have these health issues?'

These comments highlight the complexity of ethnicity and confusion around having categories based on race, nationality, and geographical region.

Heritage and health

Some community participants differentiated between choosing an ethnicity based on how someone feels as an individual and the importance of family heritage in identifying certain health conditions:

'So that's why I say look on the parents sometimes. I have a friend who couldn't figure out why her daughter was always ill, and I said what's your mother like she said [inaudible] but your daughters got thalassaemia trait and she didn't even know. But look along the parents, sometimes it doesn't matter what you've told yourself, DNA, the environment. It's your parents, or where your grandparents are from.'

This awareness is also demonstrated here:

'I think what it comes down to is what has affected your health in your family, our lineage, that's where you have to look. What you're calling yourself that has no meaning in hospital. It's down to the health issues that your parents have had or your grandparents have had that you need to look out.'

For one community participant, this understanding was related to a specific condition:

'...having sickle cell...you know, my parents are from Jamaica, so understanding those things as well, you know, isn't just necessarily the ethnicity you want to call yourself, it's the genetics of your parents or how they grew up.' It was said that family heritage should influence which ethnic category a person chooses. This led one person to question whether they were choosing the correct category to give health care staff enough detail, they used the example of the accuracy of prescribed medication. They said *'I don't know if I'm Black African or if I'm Black British, you've just thrown me all out the window.'*

It was said that more information on the connection between ethnicity and health would be useful for people to better understand the importance of collecting ethnicity data. Community participants said they would appreciate seeing leaflets and posters with easy-to-understand information in relevant places such as GP surgeries and community spaces. The discussions raised several risks.

Racial discrimination / Stereotyping

People spoke of the potential risks of providing ethnicity data and the one that came up most frequently was the risk of racial discrimination. People felt that they might be at a disadvantage by providing their ethnicity because they would be treated less favourably. This ties in to the point raised earlier around some community participants thinking that if they choose British Pakistani as opposed to Pakistani they may be viewed more favourably.

This point was raised across different ethnic groups but most notably by Black African, Caribbean and British community participants. They recognised the current inequalities in the care they receive, with one person saying:

'...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.'

Other risks around racial discrimination that people felt were present were being used as a guinea pig and being conscious of who has the data and whether it would be used to portray research in a biased way.

Someone recalled an experience they had which they felt demonstrated the racism that exists and felt their skin colour was a barrier to receiving better care:

'Because I myself, I've experienced it, where the help they are giving me, the health service I am receiving is different from that other White person to the extent that I have gone up to Parliament to bring it out, to show the racial discrimination. So, in terms of health, yes, there is a difference. I'll tell you again, oncology, you go in, you fill all those long forms. Meanwhile, you're in pain...and then a White lady walks in or a White kid or man...' what's wrong with you? Oh, you know, when I talk about chemotherapy yesterday, I was feeling a bit strange. You're here dying, you can't breathe, I need oxygen, I need this, I need that, I need fluids, I need morphine, you know, and they will get this person a bed in one minute and they will say to you 'we don't have beds let me take you to [hospital]'. So, I kind of realised sometimes it works against me.'

One community participant felt they experienced racism when they provided their ethnicity in the past which meant they no longer felt comfortable sharing it. They said:

'I used to say is 'I'm Albanian', but because a lot of people will say, have said to me, 'it's too much you don't have to always tell everyone where you're from'. So, I've kind of stopped doing that. So, I don't mention where I'm from because people have a really bad perception of Albanian people so I just don't really – now if someone asks me where I'm from talk about my ethnicity.'

Others shared the discomfort of feeling categorised and subordinated, with racism being explicitly mentioned by some and implied by others to be the cause of these feelings.

'I think it's used to pin us down to make us look like we're ill. We have health problems, and we don't. If I go to the doctors for anything, they will say, and they're filling my form out, they will say, is there any glaucoma in your family, is really diabetes in your family, is that they asked me all the health issues to do with Black, that they say Black and Asian people suffer. That's supposed to make us really ill that we're supposed to be prone to that. They ask me all those questions. And I'll go no, no, no, arthritis. No, no, no, no, no, no, nothing. My parents, my mother is 80 my dad is 86. My grandmother was 97. They don't, didn't have any of those things...they're walking strong and doing whatever they're doing.'

The risk of stereotyping was also raised as an issue for Black people; community participants discussed their experiences of being stereotyped as aggressive or dangerous. One person said:

'I've had a doctor as well, where I've been frustrated. I've been going to the hospital for 20 plus years, and I walked out of the office because I was fed up repeating myself, frustrated with him. Sometimes I'd be talking about my illness or what's going on, because I can't fully explain it and I went back the next time, he said, 'I was so worried, I thought you were gonna attack somebody'. I just told him that I'm weak, I have no strength whatsoever, you know, anytime I get angry, I end up getting, I have to control myself, and all he's thinking is that I want to attack somebody.' Another said:

'I worked for an organisation helping out, and they had a meeting with the doctors and the nurses to see what the problems were with the Black people, and when a Black person comes into hospital and the security's waiting just in case you get trouble. You could be ill, you could be sick, you're not going to hospital to make trouble but they're scared.'

Other community participants raised their concern around providing religion and did not see why this was necessary, someone said:

'If I describe myself as a Muslim, so what is the benefit you will get from me if I'm Muslim, or Christian or Jewish? So this is not describing for the personality, this is something between me and my belief, my God.'

Another said:

'I don't answer because they don't need my religion because I can understand ethnic group or something, genetic health or something, population but they don't need my religion.'

Safety of data

The second most common risk raised was around the safety of data, where it is stored, who has access to it and is it secure. Some commented on different methods of data collection, highlighting their concern over links sent via text. This concern appeared to be a consequence of the lack of information given to people around ethnicity data collection, which led people to ask a number of questions, for example, where is the data kept and who has access to it:

'...don't just tell me it's data...what is it? Let's see the statistics let's see what this data is be used' and 'they asking and collecting the data and I don't know how the data is used, what make use of that data for we just fill and give. What's the outcome? You know, we never seen any outcome.'

Sharing data with other companies was raised as a potential negative. But having data protection and safeguarding procedures in place would help avoid this and for healthcare professionals to be transparent about what happens with people's data. Community participants were generally happy for data to be shared between different health settings, for example between a GP and a hospital.

Better practice examples from community participants

There were a few examples given that worked well to address inequalities and to request ethnicity data.

Understanding ethnicity and health inequalities

To raise awareness of the link between ethnicity and health among professionals and communities, one community participant used role play to highlight what poor care looks like and demonstrate what better care looks like, in their work on health inequalities.

'We all know that when it comes to Black care, in the NHS system, we're not giving the proper care, were not looked after the same. So as soon as I know there is a black person, I've just finished doing a role play and thing on Midwifery, and how Black people are treated.'

They went on to say:

'that's the reason why we've done the play and it's, also we're doing, they're doing the, the nursing organisation and doing a big conference, so they using the play that we did, to own show and highlight these issues and how the right care the wrong care, how to do it right when it comes to people of colour, and how they've done it wrong and what they've done.'

Requesting ethnicity information

Examples of how asking for a person's ethnicity could be done better:

'Would it be better to say identify. What you identify yourself as.. because it's a perception, isn't it really. Because you might see a colour and you might be like, Oh, you're Black, or you're Brown, or whatever it is. But you might identify yourself as something else. Because you were born in a different place, or whatever it is.'

'If we ask about ethnicity is best to say... what do you describe yourself? Because sometimes they, for example, I'm from Middle East, but my sister's born in Saudi Arabia or some different places. So where do you born? It doesn't make better?'

Recommendations from community participants

As noted above, discussions with community participants were wide-ranging, covering issues related to the meaning of ethnicity, their experiences of providing ethnicity data, ethnic categorisations, and how the data is recorded and used. The following recommendations were developed from the discussions with community participants:

Understanding ethnicity

1. Ensure there is a better understanding of what is meant by ethnicity that is consistent across health organisations and those who use ethnicity data.
 - Clear comprehension will aid those asked to provide this information and awareness of associations with health conditions and outcomes.

Action for NHS England, ONS, research funders and health care practitioners

2. Ensure there is an agreed definition of ethnicity that is being used for patients to understand.
 - This needs to be consistent across health settings within the same health organisation
 - The information must be easy to understand and in different community languages.

Action for NHS England and health care practitioners

3. Create targeted interventions to improve the knowledge of ethnicity among staff and patients.
 - A range of mechanisms, including as training, should be used with staff about why the data is being collected, how it is recorded and how it will be used.
 - Improve data sharing agreements.

Action for NHS England and research funders

Explaining ethnicity

4. Introduce as standard an explanation regarding why ethnicity data is collected, how it is used, stored, analysed.
 - Implement transparency in the collection and recording of ethnicity to address patient's confidence in data collection.

Action for NHS England, data analysts and Office for National Statistics

Ethnicity and health outcomes

5. Provide a clear explanation of the wider determinants of health and how these relate to health outcomes, and the connection between ethnicity and health.
 - This needs to be accessible for all to understand using a variety of methods including easy read, visual aids, simple English and community languages.

Action for NHS England and healthcare providers

Ethnic categories

6. Ensure ethnicity categories accurately reflect the current population.
 - Patient's ethnicity needs be represented in the categories they can choose from to help address the confusion and understanding of ethnicity across society.

Action for Office for National Statistics

7. Add a 'write in' box for people to specify their ethnicity or altering existing categories to reflect continent/geographical area.
 - Enabling people to specify their own ethnicity if there was not an appropriate category available.

Action for Office for National Statistics and NHS England

8. Include members of local communities in consulting/providing feedback on any changes to ethnicity coding.

- Meaningful action should include community outreach and engagement with local communities to ensure any future changes to ethnicity categories is done collaboratively to accurately represent communities.

Action for NHS England and healthcare practitioners

Recording ethnicity

9. Practice should be put in place to ensure staff do not change the recording of a person's ethnicity as this should be self-identified by the patient.

Action for NHS England, healthcare providers, and data analysts

10. Clear policies must be implemented to mitigate against staff independently recording and/or inputting ethnicity data to replace ethnicity data that is missing.

Action for NHS England and healthcare providers

Addressing risks to providing ethnicity data

11. Address factors of trust, patients' lack of understanding of why ethnicity data is requested and fear of racial discrimination as a means of ensuring complete and accurate data is collected and recorded.

- This could be achieved through a range of community engagement activities to build trust and give explanations about why ethnicity data is collected.

Action for and NHS England and healthcare providers

12. Ensure better data management and governance of the ethnicity data recording process.

- Implement more transparency in policies and procedures particularly in relation to why ethnicity data is being collected, what impact it will have, where and who has access to it.

Action for NHS England, healthcare providers and data analysts

13. Introduce regular audits to ensure data management and governance standards are met.

- Transparency of these procedures is likely to impact on patient confidence to provide personal information when asked.
- Procedures in place must address data safety and completeness.

Action for healthcare providers

Findings from the engagement with the healthcare workforce

Engagement with healthcare workers focused on their understanding of the ethnic classifications used and the issues faced when collecting and recording ethnic data. Recommendations were obtained from both groups of how to improve the quality and quantity of ethnic data recording.

Key findings

1. It was agreed that ethnicity is important to collect and that this should be self-reported by patients.
2. All participants agreed that ethnicity must be self-identified but examples were given where ethnicity was assumed based on race or visual appearance.
3. Healthcare worker participants reported challenges to requesting ethnicity data which some participants had overcome by developing a personalised approach that aided in ethnicity data collection.
4. There was no standardised definition of ethnicity used to request ethnicity data.
5. There was no consistency in the ethnicity categories used in the healthcare organisations represented, including different settings within the same organisation. But the healthcare worker participants felt the categories were overall reflective of their local populations.
6. Categories 'unknown' 'not specified', 'not given' or 'asked but not given' were recorded on patient records, which marked that section as complete, despite not giving any clear indication of ethnicity.
7. Most participants tasked with collecting ethnicity data did not know why they were collecting the data and how it would be used. This ultimately impacted any explanations they would give to patients.
8. The potential for discrimination was an issue in ethnicity data collection and it was not clear of any safeguards in place.
9. All participants agreed that ethnicity recording was of high priority but competing priorities and resources affected the commitment to ethnicity recording.
10. There was a lack of clarity in regard to procedures to check accuracy, consistency and auditing of ethnicity data.

What patient information is recorded in healthcare settings

All healthcare worker participants agreed that demographic details must be recorded correctly for all patients, but there was no consistency in the demographic data collected across the different health organisations. The most common patient demographic data collected included: language spoken, religion, place of birth, nationality, alongside ethnicity. When compared to other demographic data, ethnicity recording was reported as lower for the majority of the health settings where the healthcare worker participants worked.

However, for some organisations, the emphasis was on other data relevant to their clinical area;

for example religion had a higher recording for those in hospice, palliative care or wards with elderly patients or respiratory care. Some health organisations had high completion of ethnicity data, for example one organisation stated they had 96% ethnicity rate recorded, but healthcare worker participants were not confident about the accuracy of the data because of a lack of auditing, and any process to address miscoding.

The following sections gives an overview of some of the practical issues and challenges healthcare worker participants experience with the recording of ethnicity data.

The problem with understanding ethnicity

We identified that:

- There was a lack of clarity as to why ethnicity data is collected.
- The majority of healthcare worker participants were not clear how the ethnicity data collected would be used

A starting point in the discussions was to explore healthcare worker participants' perceptions of ethnicity. Responses included:

'I think it's, it's how you identify yourself.'

'I think I like to think of it as more biologically and physically as me as a person as opposed to where I am located in the world.'

Some healthcare worker participants appeared to associate ethnicity with race only, for example *'the colour of your skin'* and *'I see it simply as how you would classify race'*.

No-one was able to state a definition of ethnicity being used by their organisation, adding to challenges when requesting ethnicity data from patients. But all agreed that ethnicity must be self-defined and not prescribed by anyone other than the patient.

Why is ethnicity data recorded?

There was a lack of clarity as to why ethnicity data is collected and how it can be used. Those in managerial or clinical roles or those working on health inequalities were more likely to speak of an association between ethnicity and health, giving examples related to risk of some long-term conditions.

Those who had an administrative role were less likely to convey reasons for collecting the data, as demonstrated in a session with several administrative and reception staff from a group practice. None of the administrative staff knew why the ethnicity data was requested, which appeared to surprise the practice manager who had an expectation that the reasons were well-known. Only a few administrative staff mentioned any association between health and ethnicity, primarily due to the prominence of Covid-19:

'Is it because of COVID and a lot of minority ethnic group has been affected more by COVID? I'm not sure.'

There was also the suggestion that ethnicity was recorded to assess uptake of services across different communities. One healthcare participant who worked with new arrivals and asylum seekers and refugees stated:

'Well, it's I know, it's being used is getting used for all the records to show you know, within each practice to see which communities are, you know, going to.'

The majority of healthcare workers suggested that more precise information would give a better understanding of why ethnicity is collected and recorded and would encourage all healthcare workers to make ethnicity recording a priority, as noted by one participant wanting to know the 'rationale' behind ethnicity recording:

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

How is ethnicity data used?

Some healthcare worker participants were able to clearly state how ethnicity data is used but they were in the minority. There were references to ethnicity data being used to address health inequalities, according to one participant:

'So we can target, so for example, if, if so, say so, Yemeni women, practicing Muslim women are not taking up smear, you know, opportunities, we need to understand that, you know, the data is important for us to be able to target those groups and understand culturally, why it may be difficult for those women to access those services.'

Those working on health inequalities also spoke about how a patient's ethnicity and language is useful to address communication issues. Although there was some confusion about ethnicity and language spoken, with one healthcare worker participant stating that knowing a patient's ethnicity could help their service to provide an interpreter for a patient. Others suggested that ethnicity should not be used to make assumptions about a patient's communication and language needs:

'I know someone who was she's Somali, but grew up in the Emirates and she only speaks

Arabic. So, on the form, she her, you know she is Somali but her language is Arabic. I don't think that gets recorded. I think it's just ticked Somali. And then she doesn't speak a word of Somali.'

Although ethnicity can be used to determine communication support, it must not be automatically confused with language spoken or reading in that language.

It was also mentioned that ethnicity data is a way of measuring how a GP practice is meeting requirements set out in the Investment and Impact Fund incentive scheme that supports primary care networks to deliver high quality care to their population. According to one healthcare worker participant talking about the data system that records ethnicity:

'But with a EMIS and the impact investment fund, it is ethnicities on there. So, it's all about, if you don't meet target, then it will reflect the income for the practice as well. So that is something that needs to be discussed at practice level.'

Only one participant from a GP practice mentioned using ethnicity data for research and health:

'We're a clinical research practice. So, ethnicity can be incorporated into a lot of research that we've done quite a lot of what's my story, ACE [adverse childhood experiences] research was specifically targeting like the BAME community, like you say, patients that are possibly diabetic that haven't been identified. I think that's the What's My Story, one, record and ethnicity is important because it's updated on the SCR [summary care records] record. So, hospitals, outside organisations are able to access that data as well.'

Another GP practice explained how ethnicity data is assessed and used to inform standards that are developed for primary care for certain health conditions:

'So, they will, they'll assess what we've done previous years. So, like last year, and they'll assess, and this is from a city-wide perspective, this is not just for us. So they'll see where we've been poor on and they'll bring in new standards the following year to help us improve on patients. So, for example, last year, there was a significant increase in males having strokes and dying. So, what they've done is this year, they've asked us to run IQ risk searches for patients to identify them and put them on statins.'

The problem with ethnic categories

A number of issues were raised in relation to ethnic categories used in healthcare.

- There is wide variation in the data categories used to record ethnicity in health settings.
- The wide 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.
- There is a need for the ethnic categories to be up to date with the current ethnicity make-up of the population.

Variation in ethnic categories used

Most healthcare organisations use the 16+1 ethnic data categories defined in the 2001 Census as standard to record and analyse data. These are specified in the NHS Data model and dictionary. But none of the healthcare worker participants were sure of the ethnicity categories that were used to record ethnicity in their health setting. According to one person:

‘...it’s one that’s generated on the NHS system. So how up to date that is I am not sure, but it is quite vast.’

There was wide variation. Several GP practices in one network used both 2001 and 2011 Census categories. Healthcare worker participants from these practices explained that if a category was not available in one of the sets, they would use the appropriate category in the other set. According to the performance manager, the practices:

‘Focus just on the 2011 like say when they [admin staff], when they get a registration form, they just open a new template, which has all the codes in for them, they just use the drop-down list, select whichever one than the patient’s ticked. So, I think the 2011. Although there are a couple of 2001 in there as well census, but there should be another update.’

In another region, healthcare worker participants spoke of different categories used across nine GP

practices that reflected the diverse communities they serve. Practices added other ethnic categories to the existing list based on their local populations:

‘...some GPs they, they based around some communities, so they have so many patients from certain community. So, they will add the word for the tick for example, Eritrean.’

But such variations can lead to challenges when making analysis across the regions.

In another Trust, different departments were found to use different ethnicity categories for example in outpatients:

‘So where like anybody we could take their ethnicity like it is just a drop down. And the, the ones that you can choose like, are the ones that are like the NHS data dictionary. But I noticed like with other tables, such as RTT [Refers to Treatment], the waiting list table, they do have like, they are different ethnic categories that you can choose.’

Ethnic categories are too general

All healthcare settings used a group of pre-defined categories for patients to identify their ethnicity. However, it was raised that there may be difficulties for those who are of mixed heritage/ethnicities where more than one option would be applicable. There were questions of the appropriateness of the ethnic categories for specific ethnicities such as Mauritian or Japanese, and whether the aggregated groups were too general. The latter was noted as an issue for new arrivals in the UK and their understanding of the categories in relation to race or geography:

‘Yeah, the problem is with this one, the problem with this one, it’s, it’s African you, you mentioned the place or the continent. Arab you mentioned the race. Sometimes they get mixed up between Arab and African between the African as a continent and between Arab as a race.’

Furthermore, the lack of specificity was noted to be an issue for those who worked on health inequalities. They raised that the ethnic categories were not specific enough and that aggregated categories were difficult to drill down for specific

purposes. In work to identify Black men for a prostate cancer campaign, one healthcare worker participant struggled to get the data from across a network of practices because of the categories being used:

'So if I put African, then I could come up with Tunisians, Moroccans, and the Arab communities, but they weren't the communities that I was particularly targeting. And so what we had to do was trawl through all the patients that have identified as African, and then look up those that were what we call Black African in my language in my community, and, and kind of glean the information, which is time consuming.'

The relevance of the categories was also raised in relation to newer communities and how movement or displacement was captured in the categories, and how this could impact on how some communities would identify their ethnicity. An example was given of the Kurdish community living in the UK who originate from several countries including Turkey, Iran and Iraq:

'So for example, for them where they will find themselves, they can't label themselves as Arab, they can't put themselves as African, Asian it won't capture the, they can put other as Kurdish.'

Use of arbitrary non-specific categories

Arbitrary categories of 'not specified', 'not asked', 'not stated' or 'not known' are used on all data systems. Several healthcare worker participants explained that a response in the ethnicity field of a patient's record, including the non-specific categories, is deemed as an acceptable response. There is no incentive to confirm the ethnicity of the patient at a later stage if something is already recorded in the ethnicity field. One healthcare worker participant working in the emergency department explained:

'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. So, it basically this is when the next time the patient comes in, for whatever reason, because that field was already been populated with an acceptable answer and for the last time, it won't be. It won't necessarily be asked for as standard.'

There are certain situations when these codes are used such as 'clerking the patients in' or when dealing with patients with trauma, such as in A&E where requesting ethnicity may not be an option. However, this may not be the reason why nonspecific categories are used. In one region where the data system had the options 'unknown' 'not specified', 'not given' or 'asked but not given', it was suggested that these options could potentially be used by some healthcare workers to avoid requesting ethnicity data from patients, as explained by a ward clerk:

'I think some people don't like to ask, and there's a temptation, if you were that way inclined to say 'ask but not given', you know, if you've got somebody who's got issues, is an angry patient.'

Moreover, in one Trust the computer system allowed 'not specified' to be inputted but did not record this as an acceptable ethnic category. This then led to a process of the information being highlighted as needing to be corrected, with ward clerks having to ask patients for this information because the category was not counted as recorded in the first instance.

The relevance of these non-specific ethnic category entries and the need to reduce them was raised by one participant working in maternity, where 'not known' or 'not stated' resulted in around 20% of the ethnicity data input. Only one Trust was moving away from using the 'not known' category and would be using 'not specified' instead. Use of such nonspecific arbitrary categories raises the question of how far patient records accurately reflect a patient's ethnicity and the health organisations reporting, if such categories are counted as ethnicity being complete in patient's record.

Timeliness of ethnic categories

The majority of healthcare worker participants did not think the ethnic categories were up to date or extensive enough, with one ward clerk saying the categories needed to be overhauled giving the following reason for change:

'For example, somebody comes from Spain, and they have a dark colour, or they can look English but I don't know what to use for those.'

Healthcare worker participants did agree overall that the ethnicity categories they used were reflective of their local populations and almost all suggested people would be able to fill in the ethnicity questions because people were 'used to filling in these forms' as individuals are asked for their ethnicity as a matter of course in different aspects of life. The categories were accepted as self-explanatory for patients, but a few healthcare worker participants highlighted issues:

'And I don't think there's really any way around it. But I think sometimes, there's obviously quite a lot of different categories there. And I do think sometimes patients might get a little bit overwhelmed. And, you know, as well as being asked other questions in regards to demographics as well. I think sometimes you might just get a patient, just, just pick one just to just for the sake of picking one'

Examples of how ethnicity data is collected and recorded

GP practice

Procedure: records ethnicity during consultations with patients either before or during the discussion. There is a template that staff are required to fill out with questions, including ethnicity. Ethnicity is usually already recorded, but they will ask the patient again for confirmation purposes.

One healthcare worker participant noticed that some people will ask what the (ethnicity) options are, particularly those from mixed-heritage backgrounds. Her common practice is to ask patients their ethnicity in order to make sure that the information she has on their file is correct. However, if she is pressed for time and she sees that ethnicity has already been recorded she may not ask. If it is definitely empty, she is sure to ask each time so that the record is not incomplete.

Ward clerks

Procedure: asking everyone their ethnicity to ensure all records are kept up to date and that people do not feel as though they have been singled out. Some people may find it offensive and don't understand why they are being asked.

A healthcare worker participant shared that ethnicity is a mandatory question that has to be filled in when a patient record is created, however it is possible and quite common for staff to input the 'not specified/not asked' option. She feels that collecting ethnicity is not a priority in A&E due to the rushed and urgent conditions people often

present with. Staff are likely to only ask patients their ethnicity if they've got time and sometimes cite lack of time as an excuse for not asking.

Their Trust-wide target for the completion of ethnicity data is 95%, however, this healthcare worker participant has estimated her team's current ethnicity recording completion levels to be around the 60-70% mark. Their patient data system is set up to produce a daily report that highlights the number and percentage of cases in which patient ethnicity is missing. For some staff, asking patients about their ethnicity may be uncomfortable. *'We're just told to collect data, not told how it will be used.'*

Child Health Information Service

Procedure: each day, data entry begins on a new Excel sheet which includes the recording of information on new births as per the data received from the partner hospital. This includes a range of things such as NHS number, address, birth weight and ethnicity.

The healthcare worker participant receives different data in a range of formats from patients' records as well as data from different local authorities which he reviews before transferring it between health visiting teams under his remit. He has found that out of all the data he receives, ethnicity is one of the most challenging to obtain/record. This is because there is often not much information given and when it is present, it can often be from different places. The healthcare worker participant often believes that when it comes to ethnicity, it is more likely to be left out when forms of patient data are completed.

Recording ethnicity data

Recording ethnicity was primarily an administrative task within reception duties in both primary and secondary care or for specific staff, such as ward clerks in secondary care. From our participants we found:

- The majority of healthcare worker participants had not received any training or specific information to help to request and record ethnicity data.
- Both paper and online processes were used to record ethnicity data.
- Most healthcare worker participants were aware that assumptions have been made about a patient's ethnicity based on individual perceptions and visual appearance.
- It is assumed by some that there is no need to check ethnicity already recorded.
- Ethnicity is requested from patients directly in a number of ways in different healthcare settings.
- Some health settings used self-check-in machines to record ethnicity to improve collection.

Training

Almost all healthcare worker participants stated that they had received no training or specific information to help to request and record ethnicity data from patients:

'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.'

Overall healthcare worker participants said that training and information was essential:

'Yeah, I think training for me training a staff is the key. Because without training staff, the questions won't be asked, and they won't be asked appropriately. So, for me, I think there

should be official training programmes to, to describe, you know, to explain, first of all, what is ethnicity? What is race, where we're going with all of this. To understand why it's important to ask patients. To be comfortable just asking the questions, even if you don't really know all the answers to these, and you can point them somewhere else.'

Within GP practices, others suggested training could enhance the practice service if ethnicity completion on registration is incentivised, as expressed by one healthcare worker participant who pointed out:

'...and then there's funding available within certain practice to enhance, enhance service, which I know quite a lot of practices apply for, which is money to help people complete registration forms. So, if those GPs are happy, and got that money, they should be held accountable to why these forms are being completed.'

Another healthcare worker participant who was responsible for the collection of ethnicity data in outpatients department had received training as part of the implementation of a new system and procedure to collect ethnicity data and explained:

'There was a push a few years ago, that's where we ended up with this form that we've got with this sheet that shows the ethnicities, there was a push, I think it was probably about, again, about probably about 15 years ago, to start collecting that data. And that's when this form was introduced. And the form does give them [staff] a description of why we're collecting the data. So, if they have any questions that the patient asks, hopefully this description will give them the information that's needed to answer the patient's questions.'

Further that:

'...it's laminated on all the reception desks, so it's just a laminated sheet of paper, two sides. It's got the ethnicities on one side, and then it's got some description of why we collect it. I think it's actually on our tool as well.'

It was suggested that training on ethnicity recording, why it is collected and how such data can be used, should be compulsory for all healthcare workers. The training should include helping healthcare workers to request ethnicity data from patients. A standardised form across all health settings in one Trust as well as a standardised approach to asking patients for this data. Moreover, that this training must be mainstreamed alongside other essential training for healthcare workers, similar to essential training such as health and safety.

Ethnicity recording processes/procedures

Healthcare workers tasked with recording ethnicity used different processes. Ethnicity was recorded by the patient on paper or online. One procedure is for the patient to complete a paper form and the information is then transferred onto a data system by administrative staff. But whether ethnicity is included in the patient information in secondary care organisations, is often dependent on the route of the referral. An example given from a hospital trust is that ethnicity is recorded 'automatically from the GP practice', but the situation for tertiary referrals is somewhat different:

So if a letter comes through, but it wouldn't, as part of that type letter, they probably wouldn't put ethnicity on it. And you wouldn't know that information until the patient presents.'

The participant noted that this would be the opportunity for the clinician to ask about ethnicity.

But very few clinical healthcare worker participants stated that they requested ethnicity data from patients, as the assumption is that the information would already be in the system from their GP or through their NHS number and that this would be correct.

Some clinical healthcare worker participants recorded ethnicity during consultation with a patient, as expressed by a practice nurse:

'I think in my situation in a clinical consultation, I think it's, it flows a bit easier, maybe. Whereas I think maybe if it's a receptionist asking the question and the patient may say, why do you

need to know my ethnicity, I need to see a doctor, my ethnicity? So, I think it depends on how the how and when the question is asked.'

There was a lack of standardisation of how ethnicity is requested and recorded for patients, not only across the various organisations that the healthcare worker participants represented, but also within GP practices in one network in a region:

'...across the nine practices, they've all got different, a variety of different application forms to register.' This member of staff also explained that different categories were also used amongst the practices within the primary care network. The network is trying to influence the way ethnicity data is collected and prioritised amongst the practices as one way of contributing to how they address health inequalities through standardised registration forms and guidance notes. However, given the individual governance of the GP practices, the staff member also acknowledges that *'there will be resistance from the practices to adopt and kind of implement new policies and procedures to ensure that the quality of data that the collected data quality is there.'*

Assumptions made about patients' ethnicity

All healthcare worker participants agreed that ethnicity must be self-reported and not prescribed by anyone other than the patient, but they were aware that at times assumptions were made about a patient's ethnicity based on individual perceptions and visual appearance. Examples were given of where a patient's ethnicity is used to assume the language spoken, with one person pointing out how such assumptions can also aid in thinking about how to best communicate with a patient saying:

'You do make those assumptions, because I would automatically think, oh, I'll just check to make sure that they understand the letters that are going out.'

Further, that assumption of ethnicity was said to aid some healthcare workers when looking at the number of appointments where the patient does not attend:

'...whatever that ethnic group is, you might make an assumption that they might be prone to not coming into hospital DNA a good example, I suppose, because maybe he can't understand the letter that we sent them, that kind of thing.'

Instances were mentioned where healthcare workers made assumptions of ethnicity based on the patient's race:

'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.'

'Also, I've witnessed people not asking the question, or just checking the box assumptions, about someone's identity.'

But it was also stressed by several healthcare worker participants how assumptions of ethnicity or race can negatively impact on the service a patient receives and impact of their experiences and health outcomes such as 'macroaggressions' from healthcare workers.

Ethnicity is already recorded on health databases

Often ethnicity has been recorded on a patient record in first contact with the health services, usually in primary care, limiting the need for further action in secondary or community care. According to one healthcare worker participant:

'...what happens is, we don't do too much of the recording, because we will have that NHS number. And then the whole thing will be transferred to if you see what I mean.'

There was indication by some healthcare worker participants that there was no need to check ethnicity already recorded for accuracy, as the assumption is that the information is correct, aptly summarised by one participant stating:

'When you're typing in, it has to be correct, isn't it? I mean, your ethnicity is not going to change from last year to this year, is it?'

For those who did not directly record ethnicity but where patients' records are transferred from one health provider to another setting, the inability to make or request changes to the inherited ethnicity data is an issue. For example, for those working in children's health information services, they receive information on all births from the hospital trusts in the region. The healthcare worker participant involved in children's health information explained:

'I feel like when it comes to ethnicity, and that's something that's always ever been left out.'

Asking patients directly for their ethnicity

Across both primary and secondary care, receptionists, administrators, and ward clerks were more often the staff members who would request ethnicity data from patients at the first point of contact.

Receptionists and administrative staff from GP practices would ask patients for their ethnicity as part of the registration process and follow up if the information was not clear or missing from their registration form:

'We have a registration form and a questionnaire form, that's set up with all the questions. So, we hand that to the patients, and they fill the form in. And then once the patient is registered, we put the data onto their record. What they've ticked and languages as well, what language they're like to speak as well, onto the patient's record. The document is scanned into the patient's record for our use.'

There was a similar process as part of the booking in procedure in hospitals such as in outpatients:

'We have to ask it casually, occasionally it's already there, but to nine times out of 10, we have to ask them.'

There were other procedures such as a breast screening service which used written cards to request ethnicity information:

'We've got a prefilled card with codes on it. We just say if you just look at the cards and tells us what ethnicity group you belong to.'

Ward clerks provide administrative support in hospitals. This involves speaking to a patient at their bedside to confirm information that is missing to be updated on the patient's record. Another healthcare worker participant requested ethnicity information as a Trust's complaints process where patients are asked to complete a demographic form. Supplementary explanatory information for patients on ethnicity and other demographic information was included.

Requests via self-check in machines or online registration

Some health settings used self-check-in machines where ethnicity would be requested. In one Trust, self-check-in machines are being used across their hospitals and it was explained that:

'...there's a drop down menu. And it's got different options on there. And they have to choose which one they fall under.'

However, patients do have the option to 'opt out' of providing ethnicity data in some hospital departments systems.

The majority of those working in GP practices mentioned online registration where ethnicity is also requested. But some healthcare worker participants raised the acceptancy of this process, stating that there were access issues for patients from refugee and asylum seeking communities. One healthcare worker participant who worked with: *'...the new arrivals' stated: 'I work in a daily basis with ethnicities filling the forms.'*

But suggested online systems are:

'...very complicated, it's not easy, and you have to have email, you have to have all the details to fill the form.'

Digital access remains an issue, as well as patients' understanding of what is being requested.

Examples of how ethnicity data is collected and recorded

Hospital inpatient

Procedure: ethnicity data is collected by GP.

System One is used. On the ward, the tab which holds ethnicity data is greyed out as an inactive tab. The healthcare worker participant only clarifies ethnicity if they believe it will impact something such as meals, prayer etc. Admission covers information such as faith, values, spirituality, the wellbeing, hobbies, and employment and would take 2.5 hours but these admissions are not always completed if the patient is extremely tired/frail/elderly.

The healthcare worker participant expressed that it would be difficult to change the data if they wanted to; if the data is greyed out and therefore not visible how would they be able to notice incorrect data? Equally, the healthcare worker participant is unaware of the process to get this change but believed it would require a few steps talking with centralised data staff.

Health inequalities programme in hospital trust

Procedure: filter through weekly clinic lists and target patients whose ethnicity is not recorded. Phone calls to patients where they are asked for their ethnicity among other questions to do with inequalities (disabilities) which are recorded on a spreadsheet and then patient's records are updated manually.

One healthcare worker participant noted that he is restricted by the drop-down options when asking ethnicity and often has to explain this to patients. No option to write in, technically there is the ability to add a comment to specify but this would not appear next to the ethnicity. He will record extra information such as religion but only if it is offered by the patient, the main focus remains on ethnicity. People often confuse nationality and ethnicity.

Disconnects between NHS systems mean that even if (ethnic) data is recorded at the GP, this does not transfer across to the hospital's system. Rough figure of 80% trust wide in recording of ethnicity however with the dedicated project there has been an improvement in ethnicity recording alongside a reduction in do not attend (DNAs) and a reduction in DNA variability. Biggest barrier and the biggest facilitator are resources.

Breast Screening Services

Procedure: in departments and mobile units, patients are shown a prefilled card with codes on it and asked which ethnicity group they belong to.

Ethnicity data is entered into the National Breast Screening system (database). For the past 12-15 months that the healthcare worker participant has been in post, she has noticed that mobile units are also now asking patients for their ethnicity and recording this in their electronic file. All hospitals/centres have their own systems to collect data which do not meet up until CDS (condensed readable format to aggregate).

Challenges in collecting ethnicity data

Healthcare worker participants mentioned several issues that affected collecting ethnicity data.

- Healthcare worker participants mentioned 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.
- Negative and traumatic experiences were noted to potentially affect patients' willingness to disclose their ethnicity.
- The inability to provide adequate explanations as to why ethnicity data is being requested added to the discomfort that some healthcare worker participants experienced.
- Perceiving ethnicity only with race affected who the data was requested from.

Lack of confidence/ uncomfortableness

Some healthcare worker participants who directly requested ethnicity information expressed feelings of 'awkwardness' 'embarrassment' and lack of confidence in asking patients about their ethnicity. The reasoning varied but some healthcare worker participants saw an individual's ethnicity as 'private' or 'personal' a 'sensitive question' which affected their willingness to request this information:

'I feel awful saying are you Asian, Indian, Asian, Black, mixed, black, right? It's not very nice thing to ask.'

Ward clerks from two different hospital trusts in different regions highlighted similar challenges when requesting ethnicity data from patients face to face. One ward clerk explained if the information is not recorded/missing:

'I go onto the ward and ask them, I'll just go to the patient's bedside, and I have to ask their ethnicity, what countries are born in their religion, and sometimes feel, hope not offending them.'

Overcoming such personal barriers to asking about ethnicity can lead not only to improvements in ethnicity recording, but can also positively impact on patient care and attendance. One Trust is actively implementing a health inequalities pilot project to reduce the number of appointments where patients do not attend across three clinical areas. Key to the Patient Navigator approach is ensuring the patient navigators understand why they were requesting ethnicity information and how it can be used. Through Patient Navigators, the Trust has developed an approach which is successful in gaining the ethnicity information from patients over the telephone. One Patient Navigator explained:

'So we do it every day, like, we'll filter out who doesn't have their ethnicity recorded within our clinic lists. And we will target those patients as a

priority. So, we just call them up. And we asked them, like, outright really say to them, your ethnicity is not recorded for whatever reason, because a lot of people it's, they're being referred from the GP, or from a way outside the trust.'

The project has seen ethnicity recording across the three clinical areas improved substantially over a six-month period.

It was suggested that guidance would help healthcare workers to feel confident about requesting ethnicity data; and particularly covering how to ask the question, the phrasing to use, and what explanation to offer patients. Several frontline healthcare worker participants seemed to have their own personal approach which helped patients to provide the information. A ward clerk on a respiratory ward described that:

'Sometimes I've had to really be a bit crafty as to say, what a lovely accent you've got, now, where was that? You know, because some people are not very keen on giving that information. And they're a little bit suspicious about why you're asking, Where was I born? What's my religion? Yeah.'

Patients' understanding of ethnicity

Many healthcare worker participants said that ethnicity is constantly requested and that patients understand what is being asked for. According to an administrative staff from a GP practice: *'What's your ethnicity? That would be the question that we ask? And I haven't come across anyone that doesn't understand that question as of yet.'*

But some healthcare worker participants questioned whether patients clearly understood what was being asked of them. One person working with new arrivals, asylum seekers and refugees stated:

'I work in a daily basis with ethnicities filling the forms,' but went on to say that *'Sometimes the people when we record the ethnicity, ethnicity, they're not aware of what's the concept of ethnicity.'*

Similarly, another participant said:

'We found some people don't know what it means there is, especially when people are coming to ED [emergency department], they're not feeling well, they don't always fill out the form properly anyway. This can be language barriers as well.'

This was also noted in one of the community focus group discussions where for some community participants, ethnicity was not something that was considered from the countries they emigrated from.

It was clear that the understanding of what was being asked in relation to ethnicity would impact on the answer given. Those working in health inequalities clearly expressed:

'But, but the problem is the issue is, if I didn't understand the question, I might be, not answer it correctly. So, the concept of ethnicity. Sometimes I come across it every, every, every, day, they didn't know something, even for example, I'm Arabic. If you translate the word ethnicity to Arabic, it's, it's it tells something completely different. The people they get mixed up between ethnicity and nationality.'

There were a few examples given as to how any misunderstandings about ethnicity would be addressed. One healthcare worker participant mentioned they read out the list of categories to patients and sometimes made suggestions to help the patient *'see where they feel they fit'*. But a clinical staff participant highlighted the possible impact of different perceptions of ethnicity on the answer given:

'...so we could ask a patient, what's their ethnicity? And they reply with something that's not that definition of ethnicity. And I think then you've got the problem with how you capture that data in the way we were just saying, you either put it in the other category, which is a very difficult call if you're then doing kind of high level audit of stuff, you're gonna have a lot in the other category, or you're gonna have someone go, I think they meant Black British, or I think they meant or whatever, and actually, it's totally not what they perceive their ethnicity to be.'

It was clear from the healthcare worker participants' experiences that the lack of comprehension and concept of ethnicity does not appear to be considered when requesting ethnicity information.

It was also said that patients are repeatedly asked for information, and it is likely that some experience a 'malaise' of information requests resulting in a reluctance to provide it. Alongside this is the suggestion that patients assume providing the information once is enough:

'Now, from a patient's point of view, patients assume, rightly or wrongly, that the NHS is a single organisation, but it's not, you know, it's not it's lots and lots and lots of different organisations putting information into all different systems, and everyone wanting to collect that, that that piece of information.'

The suggestion is that there needs to be a way of reducing the number of requests for ethnicity information. Overall, requests for ethnicity data should be clear and concise about what is being asked for, to facilitate the right answer from the patient.

Historic associations about ethnicity

Some community participants recalled instances where ethnicity had a negative effect on their experiences. Such experiences are likely to lead to some patient's reluctance to divulge this information. According to the healthcare worker participant working with new arrivals:

'It's, it's very, very complicated, especially around the Middle East countries. If you say the word Mediterranean, people, they didn't like that word, because it's new word it created after the Second World War. So it groups all the countries together some people they didn't feel they are part of this countries like Turkey, Turkey and Israel. If you say Arabs, Arabs, it's part of it in Africa, part of it in Asia.'

There is also the potential that disclosing your ethnicity could lead to traumatic experiences re-emerging from past experiences and the need to consider and address these when requesting information:

'...and I think it's probably the minority of cases, people have a disquiet around disclosing their ethnicity. You know, particularly somebody's coming from a background where they may have been traumatised, because of their experience of their ethnicity, perhaps in another country. But equally, even while I've been in this country, sadly, because mistrust was the main driver before reluctance in the vaccine rollout from some communities, because of their experiences, health and care services and education and the police, because people do not see this as a whole state interference issue, potentially. If they've had negative experiences with different,

different parts of what they're considering the state and the public state. So this isn't, it's about building those, those relationships, building trust, ensuring that the welcome and inclusive approach is felt from the moment the first letter sent to that patient and their family, you know, right through, it's not just a tick box exercise.'

The ability to provide an explanation to patients

There were few examples of healthcare worker participants being able to clearly explain why ethnicity data was being requested and also noted above by community participants. Those who were administrative, struggled with explanations. References to 'data recording' for the NHS or 'statistics' were usual explanations relayed to patients with one healthcare worker participant saying:

'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.'

Not knowing why ethnicity is being requested added to the discomfort that some of those tasked with getting this information experienced. A possible negative response to such requests, linked to the lack of understanding about the request, was also suggested as a challenge for healthcare workers to address:

'Yeah, I think some members of staff may not ask for those reasons, because they wouldn't know what to say if they were challenged, or they will just personally feel a bit awkward to ask about someone's race or ethnicity, keep calling it race.'

However, a group of healthcare worker participants working on health inequalities explained how engagement work had paved the way for them requesting ethnicity data from patients, because they specifically ensured patients knew why the data is be requested:

'We've done some engagement with consultation exercise around race with our patients. And, and so because we will be specific about our roles in terms of trying to improve outcomes for people, we will kind of explain and our roles and why we were asking questions, and why we would ask for people to engage and contribute to the consultation. So that paved the way for the question around ethnicity.'

A small number of healthcare worker participants had developed their own personal explanations, including that they were ‘*updating the data system*’, or that such information would ‘*help in providing the best care for the patient*’. Also, supplementary information through booklets sent out to patients as part of the complaints procedure:

‘...explains the reasons why we’re asking those questions that we send out alongside the [demographic] form.’

The association with race

Several of the healthcare worker participants suggested that ethnicity was perceived as something to ask of patients who were from a Black, Asian and minority ethnic background only. According to one participant:

‘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.’

But another stressed the concern for White healthcare workers is not wanting to ‘*offend*’ anyone:

‘And I think especially for White healthcare professionals, I think there can be kind of a lot of sort of White fragility anxiety around asking questions about as ethnicity sometimes. So yeah, I think so I think there’s sort of ... work to be done around that. And also actually just for staff to understand, both on admin staff and healthcare professional staff to understand why this is really important that we’re collecting this data.’

Whilst all healthcare worker participants recognised and agreed that ethnicity should be recorded for all patients, the racial identity of the healthcare practitioner was also highlighted as an issue in asking White patients about ethnicity, with challenges experienced by both Black and White practitioners:

‘...when you’re in the hospital, a White British person being asked about their ethnicity, and then actually taking offense to the member of staff asking, you know, what, what do you mean? Like, what am I? What, you know, you know, they, there’s that whole sort of dialogue that occurs as well.’

What influences requests for ethnicity data from patients?

All healthcare worker participants recognised the need for ethnicity recording but also identified some factors that impacted on this.

In both primary and secondary care, receptionists and ward clerks said they did not always have the time to collect ethnicity information because of the volume of patients seen or needing to pass patients onto other healthcare practitioners. Similarly in GP practices we were told:

‘And, you know, when we’ve observed some of the receptionists, it can be quite overwhelming. When there’s queues waiting up for, you know, for appointments, and then someone’s like, can I am have a form to fill out, you do get quite overwhelmed.’

The nature of the healthcare setting was noted as another factor. Those working in emergency departments mentioned this difficulty because of the need to react quickly, as well as a reluctance from some staff to request the information:

‘So I think from an emergency perspective, our staff do shy away from it. To be perfectly honest, they do. They would, they would shy away from it, and ask it only if you know, you only ask it if it’s if they’ve got time. And they’ll use that as probably excuse not to ask it ‘Oh, I haven’t got time to ask those extra questions, blah, blah, blah’ that does happen. And so, so that is definitely an issue from the emergency setting.’

Most healthcare worker participants stated that the priority focus on a patient's medical needs and dealing with the health situation at hand often pushed the recording of ethnicity into the background.

The potential for discrimination

Several healthcare worker participants talked about the potential for ethnicity data to be used for discriminatory purposes, as noted in the discussions in the community sessions. Those working with migrant, refugee and asylum seekers particularly pointed out how discrimination could impact on access to health care services:

'...there's still discriminatory practices within the NHS, it could also be a tool to kind of deny access to services for people, or people can make assumptions about people based on what it says on their form. And, you know, kind of those..., you know, macroaggressions from reception staff based on what it says on your form. So all these opinions can be formed, basically, by just looking at someone's basic information, which will include their ethnicity, so it's a double edged, kind of word.'

Some healthcare worker participants also mentioned incidents where Gypsy or Traveller patients had been registered as White British. However, one healthcare worker participant explained that for some patients from these communities, anticipated prejudice led to this miscoding by patients themselves:

'I've had the example where the system is saying White British, yet, I've gone to the family, and I know that they are for the traveling community. And we've had that conversation if we've had that conversation about ethnicity. And they are saying to me that yes, they are Gypsies, but they don't want to record that. And they worry about stigma and judgment.'

In this circumstance, the healthcare worker participant would discuss ethnicity with the patient and change the record to Gypsy or Traveller if they agreed.

Whilst knowing a patient's ethnicity could see the patient potentially experience racial discrimination, several healthcare worker participants stressed the onus must be on the healthcare provider to address this, at the same time as ensuring ethnicity is recorded as a means to address health inequalities:

'...for example, Muslim women to go and have the smear test and given them all the spiel about how we could save your life along the way. But then you come across a nurse who has no regard for their faith or the culture, you know, because of their lack of awareness. So, it's two pronged, it's like, we're trying to encourage people to say you're entitled to have a, you know, equity in your health care, but it's whether the healthcare providers are prepared to put the racism and the prejudiced and the discrimination and everything else they practice on a day to day basis aside, and deal with people as human beings. So, we've got a long way to go.'

One GP receptionist explained the procedure they would follow to mitigate against potential discrimination:

'We try to explain to them [patients] a bit more about what ethnicity, what their ethnicity is. Some patients have the queries though, as well, because they don't always want to have it recorded, because they have worries about racial discrimination. But we try to get as much information as possible and try to make them more comfortable talking about things like ethnicity and religion, race and things like that.'

Data systems

A number of discussions took place about the data systems used in healthcare, highlighting:

- Access permissions were in place to mitigate against any security risks to ethnicity data recording on IT systems.
- The functionality of different IT systems were straightforward to use for healthcare worker participants.

The main data systems used for patients' records are EMIS or System One. Snomed¹ codes are used across both these systems for reporting purposes. Some healthcare worker participants also used the Spine², Rio³ and Datex⁴ in their relevant departments. In addition to these data systems, some healthcare worker participants mentioned specific data searches, such as Arden⁵, that drew down information for analysis for a health care setting or local authority. For those in the care sector, the systems were developed in house, although one children's hospice had started to move across to System One.

But whilst the same systems were used across different settings, some experiences were different. For example, a care worker stated that despite often using the same system access was different:

'What's interesting or not, is that the way that we use EMIS it has to be different in the hospice or in the palliative care setting than in the GP. So EMIS is a GP system and it's quite difficult for us to use in certain in certain ways.'

Access to the patient database

Contrary to concerns raised by the community participants, healthcare worker participants identified no security risks to ethnicity recording on the different IT systems, due to access permissions set up on the systems, as explained by one healthcare worker participant:

'So all of our data sets are anonymised. So, you would never know who the person is, with any of our data transfers. It's not allowed. We've got, you know, really tight data security requirements. And I think for us, we would question anyone ask him for data with ethnicity in it unless it was specific for something to do with something specific. So, you'd have to have you'd have to have a rationale for being given that data at that level.'

Healthcare worker participants relayed different access and ability to view or amend ethnicity data according to their role:

'Once the patient is referred to us, yes, we will be able to. Because everybody have their login ID so that we don't go into a patient that I know you're not supposed to go into. So because of that we try to relay, to reduce that.'

But it appeared that the ability to view, request or amend ethnicity data is also dependent on what information is displayed to the healthcare worker. One clinician suggested ethnicity was not easily visible making it: *'difficult to interject'*.

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- 1 [SNOMED](#) CT gives clinical IT systems a single shared language, which makes exchanging information between systems easier, safer and more accurate. It contains all the clinical terms needed for the whole NHS, from procedures and symptoms through to clinical measurements, diagnoses and medications.
 - 2 The NHS Spine supports the IT infrastructure for health and social care in England. Every second of the day the NHS Spine saves lives. To find out more about NHS Spine, visit: <https://digital.nhs.uk/services/spine>
 - 3 The Electronic Patient Health Record used by mental healthcare professionals
 - 4 System for the reporting of incidents
 - 5 The [Ardens](#) NHS Health Checks Searches has been designed to help practices audit and report on details of NHS Health Checks, as well as enabling you to identify which patients need to be invited in for their NHS Health Check.
-

Data systems are straightforward to use

Healthcare worker participants said the IT systems were straightforward to use. There appeared to be a combination of categories, drop down boxes and free text for ethnicity recording. According to one person *'So it's just literally copying the information over [from the patient demographic form]. So, you don't have to manipulate it or anything, because what is there on the form is there on the systems.'*

However, some healthcare worker participants felt that the systems were restrictive in how changes could be made to the ethnicity field. Changes to the EMIS system were suggested by a couple of healthcare workers to improve patient records.

For example:

'Either that a red flag should come up as with other fields if ethnicity is not recorded. The system also has a prompt box for what to do next. Something like this could remind the relevant healthcare practitioner to add the ethnicity data: so if, for example, there was a system where they can add in their ethnicity needs to be recorded, or something like a little reminder, the bottom corner, then I think that would be kind of brilliant, because then if whoever goes to see the record, or works on the record, they can see oh, no, it doesn't have an ethnicity that needs to be recorded, or we need to find out what the ethnicity is.'

Prioritising ethnicity

The majority of healthcare worker participants stated that ethnicity recording was a priority for their health organisations. But several of these participants emphasised that there needs to be an understanding across both primary and secondary care of how the data can be used to address health inequalities and outcomes.

Overall, health organisations need to have a real commitment to health inequalities to address ethnicity recording:

'It's about how the practice that approach their commitment to having quality data around ethnicity, because if they're not aware of, of how it is how it impacts communities not knowing about ethnicities and being able to target particular communities for particular issues. If they're not familiar with that as a concept in terms of improving outcomes, then when it comes to them recording it, the quality of the data is not going to be it's not going to be there, they may not see the relevance.'

Moreover, we heard from participants that there should be proactive leadership to prioritise the recording of ethnicity. An example is one area that is trying to influence this across the practices in their network:

'...we're looking at, we did a piece of work around tackling racial inequality, we did a consultation in the community, where we spoke to people around their experiences around accessing GPs, one of the things that did come out was, you know, recording of data. So, we're really keen to really, as a network is to improve that.'

Those working in performance and quality management were more likely to prioritise ethnicity because of the focus on data quality and management for the whole trust. One healthcare worker participant explained that they have a data quality issue group within the Trust aimed at improving ethnicity recording. However, others mentioned competing priorities and resources impacted on whether ethnicity recording is prominent; with one healthcare worker participant describing this challenge:

'But what, from what I can see, being the only Performance Manager, there's going to be other

priorities that they're going to want me to, to work on. So I feel as if the performance itself within the trust is, is very stretched and if they do want to focus on, you know, addressing the issues, addressing the gaps, and, and, you know, addressing the problem, they needed, like a dedicated, you know, driver, a project manager person to actually work with, you know, with the operational team work with the informatics like, you know, to actually address this.'

The mandatory recording of ethnicity

Making ethnicity recording mandatory was one way suggested to raise its priority, and although some healthcare worker participants mentioned IT systems that indicates 'red dots' where information is required, putting information in the relevant field is not an indication of accurate ethnicity data, for example the use of 'not known' categories.

Beyond suggesting mandatory recording, some healthcare worker participants proposed incentivising ethnicity recording as mentioned previously. One person said:

'I think anything that means that any service, will get more money for, or are we seeing more favourably, if not more money for considering that I think will mean that the service will do that? I think services tend to be responsive to the targets that are set in place. If there are no targets set in place around quality of ethnicity data, for example, then you're less likely to ensure you're less likely to have that prioritised ahead of all the other targets that other services healthcare service have to kind of work on and follow through on.'

Ethnicity data governance

Participants also raised governance as an issue, focusing on the quality of the data and procedures for dealing with missing data:

- Overall, processes for correcting ethnicity that is already recorded were either not known, or inconsistent.
- There were some examples for auditing ethnicity data.
- Although there was variation in the process to address missing ethnicity data, there are opportunities for healthcare practitioners to address this in their contact with patients.

Correcting inaccuracies

Healthcare worker participants gave contradictory responses as to whether they would change the ethnicity already recorded for a patient if it was incorrect. Processes for correcting ethnicity already recorded were either not known to the healthcare worker participants we spoke to, or inconsistent. Some healthcare worker participants said they would make an informed decision to correct the ethnicity recorded for a patient; for example one practice nurse responded when asked:

‘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.’

Whilst another palliative care worker has corrected ethnicity data on referrals and encouraged the other workers in the team to do the same. A healthcare worker participant working on end of life was not aware of the organisation’s procedure but took an individual view as to whether to correct the data stating:

‘The process is if I know the family, for sure. And I know, we know, their faith, and then I’ll change it and then let the people who have been working with them know that I’ve done this so that they know as well. Whether that makes any difference to them or not, I don’t know. But I just thought it’s important that I’ve updated the database.’

It was clear from the various discussions that most of the healthcare worker participants acted on ethnicity through their strong beliefs

about accurate patient data, to ensure services are accessible to all and in relation to health inequalities. The following is reflective of the response from most healthcare worker participants who said there was no organisational procedure or guidance they were aware of to amend ethnicity data recorded for a patient:

‘But in terms of whether it’s an organisational thing, at the moment, it’s not, it’s at the moment, it isn’t, or hasn’t been, I’ve done everything, you know, myself with my own initiative.’

Audits of ethnicity data

The majority of healthcare worker participants were not aware of any audits of ethnicity data. One participant mentioned how they audited ethnicity data on their data systems primarily to measure the health settings performance either from previous years or regional benchmarking, and to submit ethnicity recorded data to NHS Digital.

A GP practice manager stated that:

‘... we run searches as well to make sure that where our ethnicity level is as well.’ Then went on to explain: *‘Well, the audit data, we obviously compare it and keep reviewing the audit. It’s a regular audit that we do so we can constantly compare how well we’re doing or not. And to see if we’re working well on quality.’*

Depending on time and resources another practice manager undertook spot checks on the data for completeness:

‘Yeah I look at the records. So I’ll take a sample, because we just take a sample of EMIS numbers that I know have registered in the last month or whatever the range is, I’m looking at, pull them and just see how we are doing.’

Two healthcare worker participants mentioned processes to ensure ethnicity was collected and recorded linked to the Investment and Impact Fund (see above) and another concerning process linked to the end of the financial year:

‘To be honest, I noticed it’s coming to the end of our last financial year, which was March. So, we started the new financial year, obviously in

April, and I do recall my GP practice and even the one that I was working at before sending these texts out.

A health visitor explained how an audit process looking at the accuracy of ethnicity data for Gypsy and Traveller communities, led to the updating of ethnicity codes and guidance for staff:

'So what we did was we installed a specific template for ethnicity and language that was kind of embedded within our system one processes, so that it was easier for practitioners to be able to access the template to be able to record it. And guidance went out to our champions at the time on the new templates, so they know specifically where to record it and to the other staff as well.'

However, few healthcare worker participants mentioned processes to check ethnicity directly with patients of what is recorded on the patient information system. Those that did, tended to be those in the role of ward clerks who need to obtain any missing data and update patients' records. A clinician mentioned a programme in their region which allows patients to see their health records and update their information accordingly:

'So the very keen patient who has decided to download the app and engage with it might go into that and record their ethnicity if it wasn't there already.'

However, it was not clear if the ethnicity data was checked for accuracy.

Missing data

There was variation in the process to address missing ethnicity data. Some systems alerted healthcare workers where the data is missing with prompts, but it is questionable how effective these processes are. Examples were given where missing data was flagged and despite patients being assessed at different points within a hospital, their records still had the ethnicity data missing.

There are opportunities for practitioners, such as health visitors, community nurses and other clinicians to address missing data in their contact with patients. But there appears to be no consistency in approach within an organisation or across the regions on dealing with missing data. Individual healthcare worker participants seemed to make the decision on how missing data would be followed up. An example being that of a care worker:

'So, where we have any referral without ethnicity mentioned in the referral form, we do email the team [clinical or district nurse] to help us to check on System One. And most often, they're missing on System One. 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.'

Better practice examples from healthcare workforce participants

Several of the healthcare worker participants described work that was currently being undertaken in their health setting to improve how ethnicity is recorded.

End of life/ palliative care

One organisation with a focus on health inequalities was carrying out work to look at who is using their services, what referrals are being received and how to make the services more accessible to wider communities. A focus on increasing the recording of ethnicity has seen an equalities dashboard developed that covers nursing services and hospices across the four UK nations.

'But also, we've now got our IT team in that for the whole charity has been creating dashboards for various statistics, and they have actually got an ethnicity dashboard specifically, I think that what's on it, it recorded is what has been asked by [service] staff. It's only recently that on EMIS, you've been able to draw information down from the spine. And I don't think we record our data or ethnicity data from the spine. It's all local. We can disaggregate which of the hospices nursing services are asking the questions. So we can tell whether one of the hospices has got an 80% rate or whether one of the hospitals he's got a 10% rate of asking, so that we can now move forward with that. So it's all quite new in that ethnicity dashboard has just been created in the last couple of months. But I think there'll be a there is a plan to be working towards improving that.'

Additionally, accountability is in-built to the commissioning process which includes a focus on ethnicity recording as an item in quarterly reviews with commissioners.

Health inequalities project within a hospital trust

One Trust is undertaking a project using Patient Navigators to reduce nonattendance across three

clinical areas and improve ethnicity recording within those three clinical areas.

'So, the work is a kind of it's the ethnicity recording and the preventing DNAs are, are part and parcel of the same thing. And we found an improvement in ethnicity recording the, the figures that [staff] was giving earlier. And we've also found a reduction in DNAs and a reduction in DNA variability. So kind of weekly DNA rates varied quite a lot. And we've kind of as well as reducing the mean number of DNA is we've also reduced how much they vary week on week, which kind of helps a lot operationally as well. So, so kind of the preliminary results are very positive. But they're kind of, you know, it's all part of the same picture.'

The plan is to see the project model replicated across the Trust to help increase ethnicity recording in all the Trust's specialities.

Developing resources for patients

Several information leaflets have been developed as a tool to help staff collect information and explain to patients why ethnicity data is required:

'Because some patients feel awkward with that question. So, what we've done this is this is the feedback we've had previously from staff members in the trust. So, one of the actions that we're currently doing is we've designed leaflets as well as posters. So we're in, in in the middle of just laminating them. So, what we've what we're going forward, what we're planning on doing is in each department have had the list of ethnic categories, and another sheet, or maybe on the back. So, it's a double sided sheet, laminated list of categories. On the other side, why we're collecting the data for the patient to read. And then it's easier for the staff member, what we've found is to ask not, not in all cases, but majority of the cases'

This Trust has a data group which has prioritised ethnicity recording and working with divisions and managers on the improvement plans.

Ethnicity Champion roles

A service that works in children's health and health visiting has developed champion roles within the Gypsy, Roma and Traveller communities working on several health issues, including assisting in the recording of ethnicity.

'I think because we have established Gypsy, Roma, Traveller Champion roles. They're very good at having the conversation about recording ethnicity, and we would do that routinely antenatal contact and at the new birth visit. What I found, though, it's a couple of years ago that I sort of looked into this further was that our data didn't match up to the county council or local authority data in that a lot of the times white British was being recorded, rather than actually sort of getting the correct ethnicity recorded. So that was one of the biggest challenges. And I think as well, for other practitioners, they're not always good at asking the question. So good, best practice for us is that we ask at all contacts, really, specifically the antenatal and the new birth'

Recommendations from healthcare worker participant

There were several recommendations to improve the recording of ethnicity data:

Understanding ethnicity data collection

1. Ensure that all staff are aware of need to record ethnicity data and how this can be used.
 - Implement core training or information sessions on ethnicity recording that includes what ethnicity is, associations with health, ethnic categories and the practical aspects of collecting the data, such as how best to request the data from patients to ensure consistency in approach.
 - Ensure staff are aware that ethnicity must be self-identified.

Action for NHS England and health care providers.

Explaining ethnicity

2. Ensure there is an agreed definition of ethnicity that is being used for patients to understand.
 - This needs to be consistent across health settings within the same health organisation.

Action for NHS England and health care practitioners

3. Raising awareness of ethnicity recording with patients.
 - Use a variety of methods to raise awareness to ensure there is better understanding of why their ethnicity is being requested, recorded and how this can be used for health purposes.
 - Share learning across health settings from awareness raising programmes and the impact on ethnicity recording.

Action for NHS England and health care practitioners.

Ethnic categories

4. Ensure ethnicity categories accurately reflect the current population.
 - Patient's ethnicity needs be represented in the categories they can choose from to help address the confusion and understanding of ethnicity across society.

Action for Office for National Statistics, NHS England and healthcare providers.

5. Remove the use of arbitrary non-specific categories which do not prescribe ethnicity to aid in the accuracy and completeness of the data recorded.

Action for NHS England.

6. Ensure there is a clear role to involve communities in determining how their ethnicity data is collected and recorded in healthcare.
 - Address perceived risks to providing ethnicity data such as fear of discrimination by working proactively with local communities.

Action for health care providers.

Prioritising ethnicity data

7. There needs to be a clear commitment to prioritise and improve the collection and recording of the ethnicity data across healthcare settings.
 - Action to implement this commitment must be well resourced with targets or incentives.
 - Implementation of this priority to facilitate the use of ethnicity data to address health inequalities.

Action for NHS England and healthcare providers.

Data management

8. Improve data quality by establishing clear procedures to assure and monitor ethnicity data.
 - Senior leadership should put in place procedures to regularly check the accuracy of ethnicity data.
 - Ensure staff are aware of procedures for reporting and amending incorrect ethnicity data.

Action for NHS England and health care providers.

9. Real consideration to be given to the mandatory recording of ethnicity data.
 - Health settings to ensure necessary changes to the IT infrastructure and procedures to record accurate and complete data.
 - Training to be undertaken with staff tasked with collecting and recording ethnicity.

Action for NHS England and health care providers.

Conclusion and overall recommendations

This research highlights the complexity of the understanding of ethnicity for those asked to provide this information and the issues for the healthcare workers tasked with collecting and recording it. Ethnicity data is being collected in health settings. But knowledge of why ethnicity is being collected and how it will be used, as well as how individuals are identified as belonging to a specific ethnic group, impacts on the quality and accuracy of the data that is recorded. Inconsistency in ethnicity recording within health settings in this research sample supports the findings of poor quality ethnicity data as noted in recent investigations. But there are actions that could improve the recording of ethnicity data.

The overall recommendations are:

Better explanation of why ethnicity data is being collected

There were similarities across both the communities and healthcare worker participants of the need to understand why the data is being collected, clear explanations of this, and better knowledge of how ethnicity data will be used. Addressing these issues is likely to improve the willingness and trust of communities to provide this information.

Develop better knowledge of links between ethnicity and health

Ensuring there is more practical knowledge of ethnicity and health/health inequalities amongst healthcare workers, and for communities in understandable formats.

Ensure ethnic categories reflect the current communities

The appropriateness of the ethnic categories will impact on the accuracy of the information provided by communities. There is a need to see how categories can keep pace with the changing diversity of the population.

Develop consistency in approach for recording ethnicity

Whilst there are practices being undertaken to address ethnicity recording with different communities, and in different clinical areas, healthcare workers need more support and information to implement consistent and appropriate practices to improve the quality of ethnicity data that is recorded.

A role for communities to contribute to how ethnicity is defined and categorised

Both sets of participants see a role for communities in how ethnicity data is collected but clarity is needed as to what this may be.

Appendix one

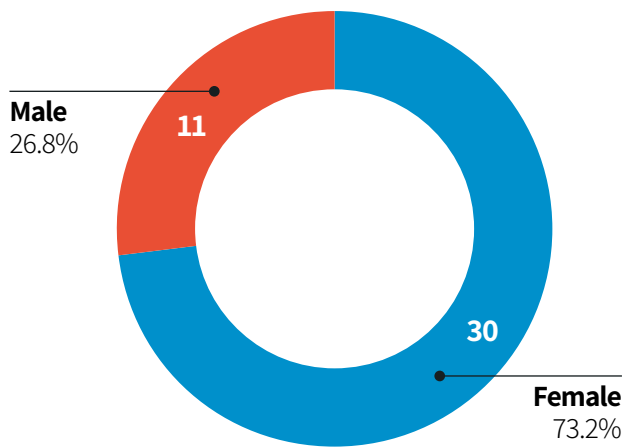
Community participants

41 community participants took part comprising of participants from a diverse range of black and minority ethnic backgrounds.

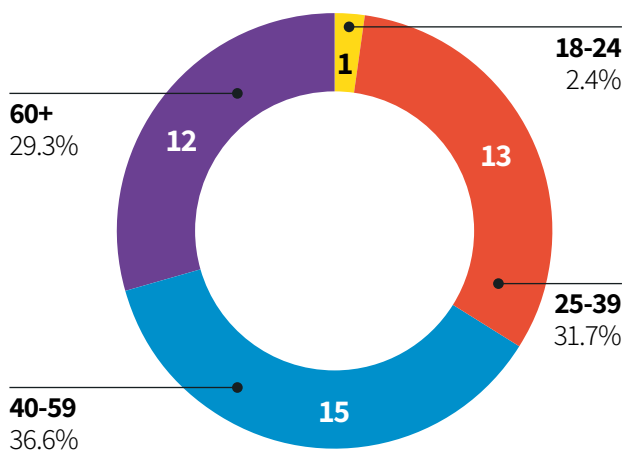
Demographic details

Demographic details were completed for all 41 participants.

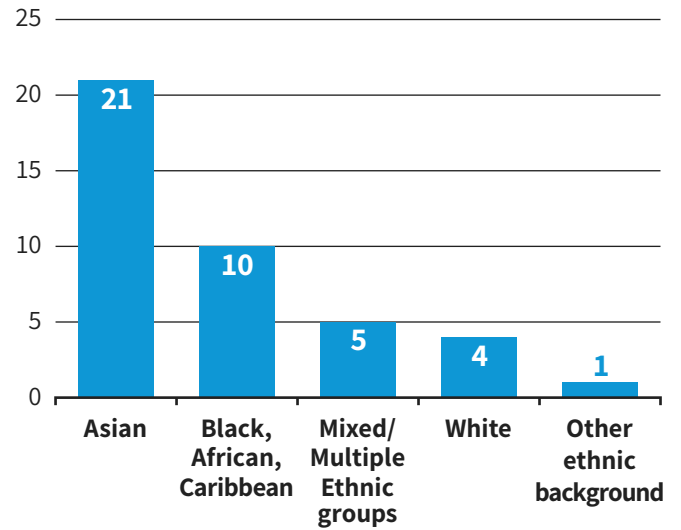
Community participants: Gender



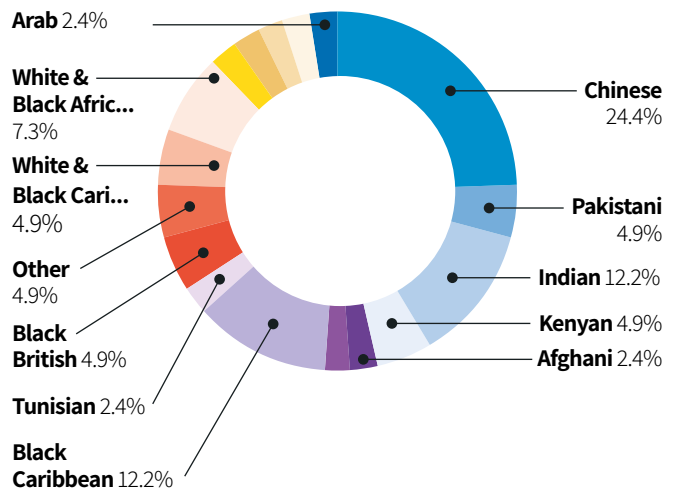
Community participants: Age



Community participants: Ethnicity



Community participants: Ethnicity



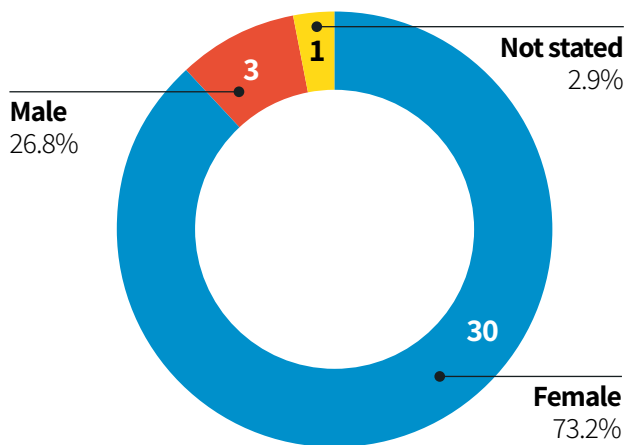
Healthcare worker participants

Participants consisted of non-clinical managerial staff; reception/administrative staff; and clinical staff working across GP practices, health visiting, child health, health complaints, hospitals settings including emergency departments, outpatients, ambulatory care, respiratory care, midwifery, community, and palliative care services. Some participants worked with specific communities – Gypsy, Roma, Travellers and asylum seekers and refugee communities.

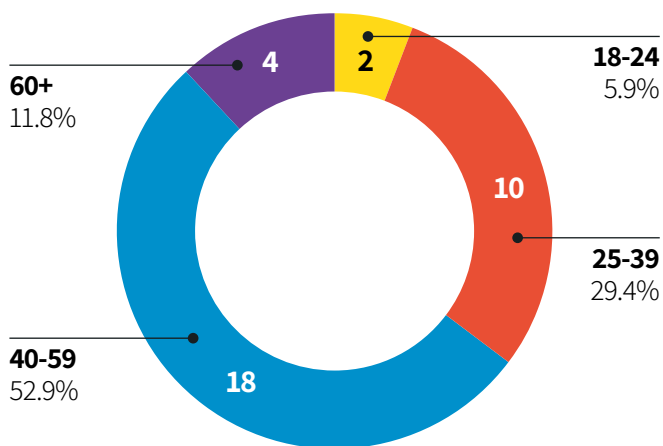
Demographic details

Demographic details were completed for 34 of the 46 participants.

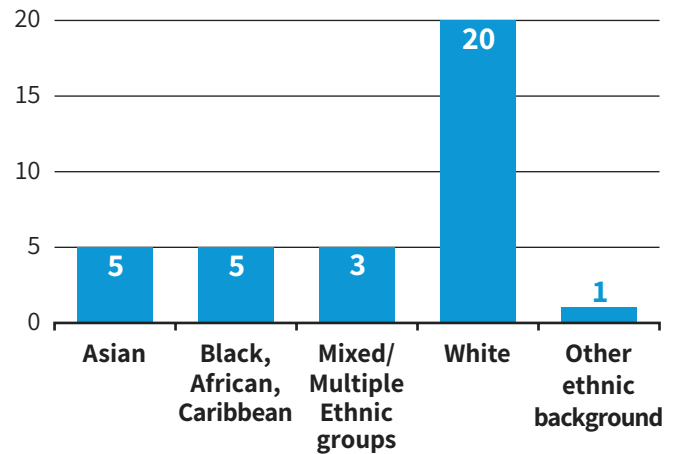
Healthcare worker participants: Gender



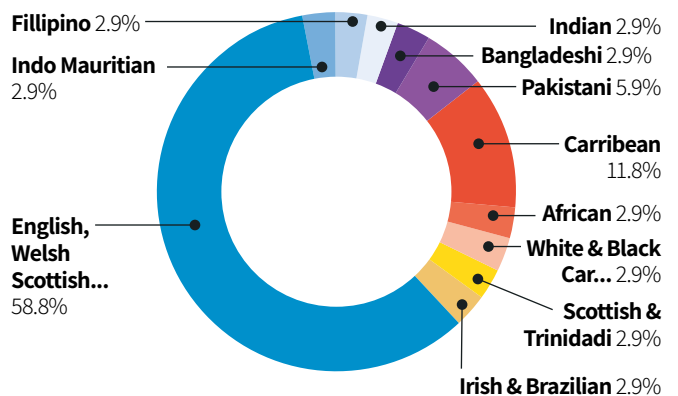
Healthcare worker participants: Age



Healthcare worker participants: Ethnicity



Healthcare worker participants: Ethnicity



Appendix two

Topic guides

Community focus groups

The following topic guides were used to instigate discussion over three sessions with community participants.

Session one

Overview and background to the project including outcomes.

Introductions

We're going to start by getting to know each other a little bit. We will go around the room and ask you to introduce yourself by saying what your first name is and tell us a bit about this.

So maybe what you know about your name? Who gave it to you? Does it have a meaning? Are you named after someone?

Facilitators to input: *Names are often a unique way of identifying who we are, but they can also be a way of telling us and other people about the groups and communities we belong to.*

Exploring ethnicity

Exploring how a range of people understand the meaning and purpose of the ethnic classifications used, and relate the categories to themselves

- Ask participants to describe themselves in five words. They have 2 minutes to do this (can ask them to write this down). From this we can look to see if their ethnicity is included and ask why people did or did not include this in the description
- What do you think ethnicity means
 - How do you think ethnic data is used for health? Have you had any explanation about how the data would be used?
- What do you think makes up your ethnicity? *show dictionary definition* - do people agree with this definition?
 - How does this link with your identity?

- Besides the form that we asked you to fill in, can you remember the most recent occasion you were asked to provide your ethnicity?
 - What was it for? Can you describe how you were asked? Where you presented with any options or given a leaflet?
- Why do you think we need to record ethnicity information?
 - How do you think ethnic data is used for health? Have you had any explanation about how the data would be used?

BREAK - 10 mins

How is ethnic recording associated with health outcomes?

Exploring how and why people's own ethnic group identification varies over time.

- 1. You completed a monitoring form including your ethnic background. Do people feel comfortable with the categories they completed? (Refer to information complete previously)**
- 2. Do you understand the different ethnic categories? Were you able to identify with one of the ethnic categories provided?**
 - What did you think about the ethnic categories used? did people easily identify with them? if not, why? Any terms offensive?
 - Are there any ethnic categories you think would work better? Why?
- 3. Has there been any explanation about the different ethnic categories?**
 - *Have list of ethnic categories used in the Census (A3 size)*
- 4. How have you identified with the different categories?**
 - Has there been any change over time? (*Have copy of 2001 & 2011 categories*)
 - Explore understanding about the difference in what is being asked e.g. some ask for Black British, black Caribbean, other category

5. **What influences how you describe your ethnic category in a health setting?**
6. **(Explore costs and benefits - whether the context of the data collection have an influence. Eg. if in a sickle cell clinic, will those with sickle cell be more likely to answer the question?) - relate discussion to conditions that affect particular ethnic groups eg dementia, CVD**
7. **In terms of the data that is collected on patients, what do you think the benefits are in giving your ethnicity data?**

- What about risks? (explore thoughts about security/trust) How do people feel any risks can be mitigated?
- *Look at example of where ethnicity data was recorded incorrectly for kidney condition (read out or give participants a copy to read themselves) – what do people think about this? Any change in thought about ethnic recording from what was said previously?*
- *Give another example of how they used ethnicity data to identify communities at higher risk of Covid-19. Explore whether participants understand why ethnicity data was used.*

Session two

Recap on project and last session

1. Your own health and care experiences of providing ethnicity data

- a) *The experience of being asked for or providing information about ethnic group through different methods and in different settings*
- At the last session, some of you mentioned being asked about your ethnicity in particular situations. Could you tell us about the last time you were asked about your ethnicity in a healthcare setting?
 - Who asked you to provide it? (e.g. doctor, nurse, receptionist, administrator). Did they help you/explain why it was needed? Would having an explanation on why your ethnicity is needed affect your decision to provide it?
 - How do you feel about providing information on your ethnicity for healthcare reasons? How comfortable are you doing this online/over the phone/in person?

- Do you think there is a link between ethnicity and health outcomes? (*eg. African Caribbean -high blood pressure, prostate cancer, South Asian - diabetes, coronary heart disease, Chinese - hepatitis B, CVD*)
 - What are some of the main challenges faced by people from your ethnic group with regards to their health? How can these be addressed?
- Do you think it is important/more necessary to provide your ethnicity in certain healthcare contexts?
 - In what ways do you think ethnicity/ ethnic groupings influence healthcare services?

(eg. early on in the pandemic pulse oximeters were being given up and deemed safe. But they did not work well on darker skin. The medical regulator had to revise the instructions)

2. Ethnic categories and perceptions

b) *How and why an individual's own ethnic group identification and other people's perceptions of them differ.*

- Has anything changed in how you describe your ethnicity in the last 10 or 15 years?
 - What/who influences changes in ethnic categories? (*time? repeated asking in different health settings*)
- In what ways might any of the following affect your ethnic identity:
 - Religion/culture (e.g. Jewish, Sikh)
 - Country of birth, nationality and citizenship (e.g. being/becoming British)
 - Language
 - Geographic location
- If we look on a wider level, say within your family, is there a difference in how you and they identify in terms of ethnic classification? Why is that?
- Have there been occasions when others have noted your ethnicity in addition to/instead of you? Was there a difference in how they see you? (Can refer back to the example of the kidney patient).

BREAK - 5/10 mins

3. Recording ethnicity

- What do you think about how staff record your ethnicity in your health records?

Hand out vignettes. Discuss: Do you think it is important to record ethnicity in each of these situations? Why, why not? Was it appropriate for the paramedics to record Thomas's ethnicity in this way? Which ethnicity category do you think is the correct/most appropriate to record for Rita?

- How content are you with the way in which ethnicity data is currently recorded?
 - How important is it to you to have a predefined box that accurately reflects your exact ethnicity (as opposed to being to specify under the category 'other')?
 - Do you believe that the current ethnic categories are self-explanatory? (Refer to 2021 census categories e.g. under Asian category, Any other Mixed or Multiple ethnic background, use of racial groupings, nationality and citizenship to describe ethnicity - *put up A3 copy for participants to view*).

Refer to example table of ethnic category changes between 1991 and 2021. Discuss: Is it ever acceptable to record a self-disclosed answer based on previous census responses? Go through examples in table one at a time (use separate handout of each person)

- What improvements would you suggest be made to the way ethnicity is recorded?
- What would a good ethnicity data collection question look like?
- What safeguards are needed to make sure the correct information is recorded?
- Is there a role for communities in determining how healthcare staff should collect data?
 - How do you think staff can work with communities in collecting ethnicity data better?

Exercise – discussion of vignettes

Scenario 1

Thomas is a 45 year old man who lives in Birmingham. He has a family history of diabetes, but does not often visit his doctor unless he feels very ill and only with his daughter's persistent encouragement. A few weeks ago, Thomas became unwell with fever and experienced sharp abdominal pains. He was rushed to hospital in an ambulance and the paramedics recorded his ethnicity as Black British, based on his name, accent and visual appearance. Upon reaching the hospital, Thomas was asked by a junior doctor to verify his ethnicity, to which he said he identified as Black Caribbean. His daughter was also asked for this information separately by the ward nurse whilst in the waiting room and stated that Thomas's mother is Black Caribbean and his father was Black African.

Questions:

- Do you think it is important to record ethnicity in this situation? Why, why not?
- Which ethnicity category do you think is the correct/most appropriate to record for Thomas?

Scenario 2

Rita is a 76 year old woman living in Nottingham. She has asthma and is also on medication for high blood pressure. Rita has recently been diagnosed with glaucoma and referred to a new optometrist. During her first visit, she was asked to fill in a form which included a range of questions, such as age and ethnicity. Rita moved to the UK from Trinidad at the age of 18 and both her parents are of Chinese Indian heritage. After a few minutes thinking about it, Rita was still unsure what to do, as although there were more than 5 boxes that she could potentially choose from, none of them of the options listed matched her ethnic identity. When she explained the situation to the Optical Assistant who gave her the form, she was told to "tick the closest box".

Questions:

- Do you think it is important to record ethnicity in this situation? Why, why not?
- Which ethnicity category do you think is the correct/most appropriate to record for Rita?

Ethnicity and health: additional information

1. People of Black African origin are up to three times more likely to develop type 2 diabetes than people of White European origin. In addition, some of the features of type 2 diabetes differ slightly in people of Black African origin.
2. People of Black Caribbean origin are even more likely to develop certain types of diabetes than compared to Black people of (West) African origin.
3. Having diabetes makes it twice as likely that a person may develop glaucoma.
4. People of East Asian heritage experience the highest rate of blindness in the world from one of the two most common types of glaucoma.

Exercise – concerning re-recording self-disclosed ethnicity

| | 1991 | 2001 | 2011 | 2021 | Coded as: |
|------|---------------------------------------|---------------------------------------|----------------------------------|----------------------------------|-----------------|
| Cam | Any other ethnic group (Libyan) | X | Arab | Any other ethnic group (Libyan) | Arab |
| Bola | X | Black African | Black African | Black other - (Nigerian British) | Black African |
| Tina | Chinese | Chinese | Any other ethnic group (Chinese) | Any other ethnic group (Chinese) | Asian - Chinese |
| Lee | Any other ethnic group (Romany Gypsy) | Any other ethnic group (Romany Gypsy) | White - Gypsy or Irish Traveller | X | White - Roma |

Here are some examples of ethnic category changes.

Is it ever acceptable to recode a self-disclosed answer based on previous responses?

X – ethnicity not recorded

Session three

Summary of sessions 1 and 2

In the previous two focus groups, we spoke about... and from what we understood, the main topics that were most important to you were... *[can relate to issues from specific focus group sessions]*

1. Understanding what is meant by 'ethnicity data'

- Not everyone understands how ethnicity data links to health (outcomes) and why
- Understanding of ethnicity can vary from person to person. There are variations between what the ONS means by ethnicity and what most people, particularly those from (historic) migrant populations, understand by the word ethnicity.

2. Accuracy, representation, categories

- There is some confusion surrounding what constitutes ethnicity and why certain ethnic categories have been chosen (representation).
- Some/many people felt that the ethnic categories listed (1991/2001/2011/2021 census) still do not accurately reflect their ethnicity/heritage/culture.
- It was repeatedly suggested that new categories/boxes should be added dependent upon population/diaspora sizes.

3. Completeness

- Some people choose not to fill out their ethnicity for various reasons.
- There was general agreement that changing the recording of ethnicity is unacceptable under any circumstances and that what people write-in should be used. Any blanks/unfilled boxes should be left as blank, even if healthcare staff believe they can accurately describe a person's ethnicity.

4. Data management & governance (including safety, storage and sharing)

a. People do not receive satisfying explanations as to why ethnicity data is needed which influences how likely they are to provide it (in certain health contexts).

Ask participants: **Is this correct? Have we missed anything?**

- **Key question: How** can we ensure that ethnicity data is clear, consistent and managed well?

1. Increasing understanding of ethnicity (individuals and staff)
2. Governance and data accuracy
3. Best format to ask about ethnicity
4. Consistency of data

- **Develop recommendations based on above discussions**

Healthcare workforce participants focus group topic guide

Session one

Overview and background to the project including outcomes.

Participants to introduce self and their role with ethnicity data

We recognised that you all do different jobs and your part in the recording of ethnicity might differ. some questions may not refer to you but we're trying to get a full picture what the actual situation is with ethnicity recording

1. Recording of ethnicity

- Can you remember the most recent occasion you asked someone to provide their ethnicity? In what context did you ask? Was this in person, over the phone, via text etc?
- How do patients record their ethnicity in your health setting? Are they asked? Are they given a form to complete?
- What information have you been given about how the data that you collect is used?
 - Prompt: Do you know why it is required and how it is used? What system, standard or template/categories do you use to record ethnic categories?
 - Prompt: Have you heard of the 16+1 ethnic data categories defined in the 2001 census? This is the national mandatory standard for the collection of ethnicity in England (including NHS)

2. Understanding of ethnic coding and categories

- Can you tell us what information you record on patients? (e.g language, religion)
- What do you think ethnicity means (Jot down on board)
- What do you think makes up ethnicity? (*jot down on board*)
- Who or what has influenced your definition of ethnicity?
 - *Prompt: Have you been provided with a formal definition or training to understand ethnicity or is this based on informal understanding (e.g. media, family, school, community etc)*
- **Show dictionary definition** - do people agree with this definition? why? why not?
- **Slide: List of Census categories 2021** - Do you feel that the categories are self-explanatory?
 - *Prompt: In your opinion, are they easy for patients to fill in independently? Are they reflective of the communities you serve? Are they useful for the clinicians/staff in your setting? What would you find more useful in categorising ethnicity?*

3. Understanding of relationship between ethnicity and health

- What is the relationship between ethnicity and health?
 - *Prompt: How do certain conditions affect different ethnic groups? Examples include high blood pressure, Covid-19*
- How do you think ethnic data is used for health?
- What do you think are the benefits/risks in collecting ethnicity data? How might any benefits be amplified?
- How do you feel any risks can be mitigated?
- **Example of vignette:** Do you think it is important to record ethnicity in each of these situations? Why, why not? Which ethnicity category do you think is the correct/most appropriate to record for Rita?

BREAK 5 mins

4. Confidence in requesting and accurately recording/monitoring ethnicity

- Past research has found that some workers feel uncomfortable asking patients about their ethnicity. What is your view of this? How easy/challenging do you find requesting patients' ethnicity information? (Prompt to give detail/examples/reasoning)
- How confident are you to request ethnicity data from patients/service users?
- How confident are you in explaining why you are requesting ethnicity data from patients/service users?
- What influences whether or not you request ethnicity data from a patient?
- Does the setting you work in, or the nature of the patient's visit have an influence?

E.g. how likely would you be to request the ethnicity of a patient with sickle cell, in comparison to someone who did not have the condition?

- What explanation is given to patients about the need for requesting ethnicity data? How do you manage incomplete ethnicity forms?
 - What are your views on recoding/filling in missing or 'questioned' data?

Refer to the example table of ethnic category changes between 1991 and 2021. Discuss: Is it ever acceptable to record a self-disclosed answer based on previous census responses? Go through examples in table one at a time .

- What improvements would you suggest be made to the way ethnicity is recorded?
- What would a good ethnicity data collection question look like?
- What safeguards are needed to make sure the correct information is recorded?

5. Practical considerations

- How much of a priority is recording ethnicity data to you?
 - Do you have allocated time to input/update the data you collect?

- Have you received any training on how to request, record or input ethnicity data?
- What are the key challenges you face/have faced in recording ethnicity data?
- How clear/useful is the data entry system you use for recording ethnicity?

Session two

Recap of project aims and outcomes

1. **Can you remind us what the process is for where a patient's ethnicity data is missing in their most recent contact with your service?**
 - How do you check the ethnicity data? Do you engage with the patient to get this data? would you go back to the service that referred them?
 - If there is a difference between the ethnicity a patient specifies in data that is inherited from another NHS service (eg. Spine, EMIS) to what you have been told by the patient, what happens then?
 - How would you deal with differences recorded in different health/care settings or systems to your own? What is then recorded for patients? Is there a difference in what you are required to do (by your organisation) and what you do personally (using your own judgement)?
2. **How do you deal with gaps in ethnicity data?**
 - Are assumptions made about ethnicity based on other factors e.g. visual appearance, names? Does the system prompt you to check?
3. **In terms of other patient information such as religion, sex, age, how complete would you say this information is on patients records?**
 - Will the system allow you to move on if one of these fields, e.g. date of birth is incomplete?
 - How does the system deal with other aspects of patient information that is missing? Is it compulsory to complete these? will they be flagged? Which ones are necessary? are some a priority more than others - eg date of birth opposed to ethnicity?
4. **How is ethnicity data regularly audited for accuracy and completeness? sending text/letters to ask patients for their ethnicity again? a system audit? How often (linked to financial year?)**

5. **We now want to look at whether it is ever acceptable to record a patient's answer based on previous ethnicity responses? Go through examples in table one at a time**
 - What safeguards are needed to make sure the correct information is recorded?
 - Is there a role for communities in determining how healthcare staff should collect data?
 - How do you think staff can work with communities in collecting ethnicity data better?
6. **Finally, are there any other improvements than what you suggested previously should be made to the way ethnicity is recorded in healthcare?**

Recording of ethnicity - workforce interview

Introduction to the project

Please introduce yourself and tell me about your role with ethnicity data

1. Recording of ethnicity

- Can you remember the most recent occasion you asked someone to provide their ethnicity? In what context did you ask? Was this in person, over the phone, via text etc?
- How do patients record their ethnicity in your health setting? Are they asked? Are they given a form to complete?
- What information have you been given about how the data that you collect is used?
 - Prompt: Do you know why it is required and how it is used? What system, standard or template/categories do you use to record ethnic categories?
 - Prompt: Have you heard of the 16+1 ethnic data categories defined in the 2001 census? This is the national mandatory standard for the collection of ethnicity in England (including NHS)

2. Understanding of ethnic coding and categories

- What information do you require to be recorded for patients? Prompt: ethnicity, language, religion?

- **In terms of other patient information such as religion, sex, age, how complete would you say this information is on patients records?**

- Will the system allow you to move on if one of these fields, e.g. date of birth is incomplete? Is it compulsory to complete these? will they be flagged? Are some a priority more than others - eg date of birth opposed to ethnicity?

- What do you think makes up ethnicity? (jot down on board)

- Who or what has influenced your definition of ethnicity?

- Prompt: Have you been provided with a formal definition or training to understand ethnicity or is this based on informal understanding (e.g. media, family, school, community etc)

- **Show dictionary definition** – what do you think about this definition? Do you agree with it?

- **Slide: List of Census categories 2021** - Do you feel that the categories are self-explanatory for patients?

- Prompt: In your opinion, are they easy for patients to fill in independently? Are they reflective of the communities you serve? Are they useful for the clinicians/staff in your setting? What would you find more useful in categorising ethnicity?

3. Confidence in requesting and accurately recording/monitoring ethnicity

- Past research has found that some workers feel uncomfortable asking patients about their ethnicity. What is your view of this?

- Prompt: is this something you are aware of? How easy/challenging do you find requesting patients' ethnicity information? Confidence to explain why data is needed? (give detail/examples/reasoning)

- Does the setting you work in, or the nature of the patient's visit have an influence on whether you request ethnicity data from patients? How?

E.g. how likely would you be to request the ethnicity of a patient with sickle cell, in comparison to someone who did not have the condition?

- What explanation is given to patients about the need for requesting ethnicity data? How do you manage incomplete ethnicity information?

4. Practical considerations

- How much of a priority is recording ethnicity data to you?

- Do you have allocated time to collect/ input/update the data in your role?

- Have you received any training on how to request, record or input ethnicity data?

- **How clear/useful is the data entry system you use for recording ethnicity?**

- How would you deal with differences recorded in different health/care settings or systems to your own? What is then recorded for patients? Is there a difference in what you are required to do (by your organisation) and what you do personally (using your own judgement)?

- How do you check if the ethnicity data on record is correct?

- What do you do if ethnicity data is missing?

- What is the process for auditing ethnicity data for accuracy? sending text/letters to check with patients? checking with service that referred them? how often does checking occur?

5. Finally, are there any improvements you would suggest to collecting ethnicity data?



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