Healthcare Improvement Scotland

Anti-racism plan–Engagement Report

Experiences of patients from minority ethnic groups in accessing NHS Scotland services

February 2025

NHS SCOTLAND

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1. Introduction

1.1 About Healthcare Improvement Scotland

Healthcare Improvement Scotland is the national improvement agency for health and social care in Scotland. We lead improvement in the quality and safety of health and care for the people in Scotland using our skills and knowledge to tackle the quality challenges being faced. Our role is to be at the heart of national efforts to understand and shape the quality of health and care, and with partners, to embed quality management across the provision of health and care. Our support for the system is underpinned by a number of statutory duties and powers, including:

- to further improve the quality of health and care
- to provide information to the public about the availability and quality of NHS services
- to support, ensure and monitor the discharge of health bodies' duties in respect of public involvement
- to monitor the quality of healthcare provided or secured by the health service
- to evaluate and provide advice to the health service on the clinical and cost effectiveness of new medicines and new and existing health technologies.

1.2 About this engagement

All NHS Scotland boards, including Healthcare Improvement Scotland (HIS), have been asked by the Scottish Government to develop their own anti-racism plans. These plans should cover both workforce issues and racialised health inequalities, and it is important that the plans developed are informed by minority ethnic communities themselves.

At Healthcare Improvement Scotland, we have worked with our internal staff Race and Ethnicity Network to develop a plan to review and address issues within our own workforce. We also want our plan to reflect our role as the national health improvement agency in addressing racialised healthcare inequalities that are well documented across a range of existing studies. We wanted to use our community connections to understand the experiences of patients from minority ethnic communities across Scotland and what matters to them about accessing health and care services.

We know that different organisations have undertaken engagement around this theme in recent years and in relation to specific health services. We have reviewed available reports as part of developing our anti-racism plan. Our Community Engagement and Transformational Change directorate has been working over the last year to diversify our local community contacts including minority ethnic groups. We want to ensure a range of people and communities understand how they can influence healthcare policy in Scotland. We wanted to engage some of our local contacts to hear more about their recent experiences with NHS services and what matters to them. Our aim was to build on existing findings and explore issues experienced by people in local communities and so this was a highly focussed exercise. The voices of the people we spoke to have shaped this report. We expect this report will make a useful contribution to existing engagement evidence and allow

us to better understand the communities we are in touch with and hope to work with over future years.

The report that follows explains how we approached this engagement and what we heard from those who participated. We provide some general recommendations based on our findings and describe how we will take the findings on board as part of our own anti-racism plan.

We are very grateful to all our engagement participants for taking the time to share their experiences and reflections with us, and to the community groups who supported our engagement by sharing information about it and supporting their members to take part. We hope this report provides a good account of what we heard and what we will do. We look forward to staying in touch with the community groups who helped and to continuing to build our understanding of healthcare and inclusion together.

1.3 Anti-racism and our language

We first want to explain what we mean by 'anti-racism,' which is the focus of this work. We will also explain our approach to language in this area.

Racism is prejudice, discrimination or antagonism by an individual, community or institution against a person or group of people due to their membership of a particular racial or ethnic group. We know that racism influences the life chances of people from minority ethnic groups and drives significant disparities in the quality of health and care for the people of Scotland. This includes inequality in access to and experience of health services, compared to Scotland's majority white ethnic group. The disadvantage that people from minority ethnic groups experience comes from bias in the system as well as the personal attitudes of its employees. Racism accounts for all of this and is so ingrained in our society and its history that it is not always intentional.

Healthcare Improvement Scotland committed in our 2023-2028 strategy to being an anti-racist organisation. We join our colleagues across the Scottish health and care system in making this commitment as overcoming the persistent reality of racialised health inequalities is finally prioritised as part of the health policy agenda.[1]

By 'anti-racism' we mean challenging racism wherever we see it, both in our workplace and as part of the work we deliver to support Scotland's health and care system. It means noticing disparity and thinking critically about personal and system approaches. We see 'anti-racism' as an active position where we look for and change the disadvantage people from minority ethnic groups experience. We did not ask about our participants' understanding of racism. We were instead interested in their experiences as people from minority ethnic groups, what we might notice in their experiences and how we can respond.

[1] Anti-racism plans - guidance

Along with the Scottish Government, we recognise that across Scotland people belonging to minority ethnic communities define themselves and their communities in different ways. They may also have different experiences of racism. Wherever possible in our work, we try to avoid using collective terms that group various minority ethnic communities together. Our engagement exercise however is not extensive enough to properly represent the distinct experiences of different communities. It instead identifies broad trends and experiences that may be shared by different communities as they engage with the NHS in Scotland. We therefore refer most often to 'minority ethnic communities' and participants from 'minority ethnic groups' meaning those people and communities most likely to experience racism and its related health inequalities.

2. Approach

Healthcare Improvement Scotland's Community Engagement and Transformational Change Directorate has a range of community engagement tools that enable people to have a say in our work and inform the development of health and care policy and services in Scotland. One of the approaches we use is called Gathering Views.[2] This approach aims to gather lived experience views on specific subject areas to inform decision-making. Further information on our Gathering Views processes can be found on our webpage. While our Gathering Views exercises are usually carried out to help inform national policy development, we adapted the approach to engage with people from minority ethnic communities about their recent experiences of NHS services. Our aim was to gather insights about the experiences people have had as patients from minority ethnic groups in Scotland to identify existing good practice and needed improvements to inform Healthcare Improvement Scotland's anti-racism plan and approach.

Since April 2024 we have been working across the whole of Scotland (divided regionally by North, East and West) to build and maintain relationships with diverse communities, including geographical communities, protected characteristic groups and communities of interest. As part of this we have built relationships with twenty-six minority ethnic groups. Over a five-week period between 7th October and 18th November 2024, we reached out to minority ethnic groups to invite individual engagement participants to reflect on their recent experiences engaging with NHS Scotland services through the lens of their minority ethnic background.

2.1 Who we engaged with

We wanted to hear from participants who met the following criteria:

- Identifies as part of a minority ethnic group in Scotland–here we included anyone who is not white Scottish, British or Irish. We included anyone with a mixed ethnic background too– for example, Scottish Asian.

[2] On behalf of the Scottish Government and Healthcare Improvement Scotland, views are gathered from members of the public across a variety of health-related topics.

- Had used an NHS Scotland service within the last 3 years and at least once between August 2021 and August 2024. We included anything from visiting a General Practitioner (GP), attending a hospital appointment or staying in hospital to receive care or treatment. We were not exploring specific services, but rather overall experiences and trends.

- Happy to talk about their experience using NHS services as someone with a minority ethnic identity.

Overall we managed to speak with sixteen people who met our participation criteria. To understand the diversity of this cohort, we asked all engagement participants to anonymously complete an equality monitoring questionnaire (Appendix 3). Participants could complete the survey either before or during the discussions, via email or using a paper copy. This achieved a 31 % response rate and so we are not able to draw any robust conclusions about the diversity of our participant cohort. We found that in the sample of participants who shared this information:

- 80 % were female

- Ethnic identities included Asian, Indian, African, mixed. In addition, we know we heard from some members of the Gypsy Traveller community

- Religions included Christian, Roman Catholic and Muslim

- Participant ages ranged from 26–65

- 60 % of participants identified as disabled or said they have a long-term illness.

2.2 How we engaged, including limitations

We promoted the engagement opportunity through our community networks, including direct email to organisational contacts. We also created a flyer which was shared by some contacts through their networks. Registration and scheduling of interviews was managed through an online form which individual participants could complete themselves. Our staff members however supported some participants to share their details and interview preferences in a way that felt more suitable. This included email and phone contact. All participants received a confirmation email and a named person who could respond to any questions in advance of the engagement interview.

The question set was developed to help us to gather people's views, insights and experiences in using the NHS in Scotland. We asked a total of six questions. An information sheet was also provided to participants alongside a consent form to take part in the work (Appendix 1). All participants provided written or verbal consent in advance of the interview (Appendix 2).

After promoting the engagement opportunity, we received some requests for group engagement where communities felt this would be an easier or more comfortable form of engagement. As far as possible, we accommodated these requests and offered multiple

participants the opportunity to share their experiences as part of a group setting. The engagement methods we used included:

- **one-to-one engagement interviews:** Six one-to-one interviews via MS Teams or telephone
- **one group discussion:** Project team colleagues met with a group of seven members of an asylum seeker support group along with their key development worker
- **one representative discussion:** A development worker collated the experiences of views of three individuals identifying as gypsy travellers.

While we were pleased to have been able to accommodate the different needs of engagement participants, we have considered that for future engagement exercises we should include contact organisations in our planning process to ensure we have the best engagement methods in place from the beginning.

It is also worth noting that we did not focus on any specific NHS Scotland services or board areas or on the experiences of specific ethnic groups. Our findings are therefore a general snapshot of the experiences of minority ethnic patients across NHS Scotland. We would recommend future engagement explores specific service-related challenges in the context of ethnic health disparities and anti-racism.

2.3 Analysis

The themes that emerged from the questions can be found in the findings and recommendations sections of this report. We have used anonymised quotes from participants throughout to support our analysis and ensure their voices are heard. Our analysis was carried out in three stages:

- We took notes and captured direct quotes during participant engagement. Engagement sessions were digitally recorded where possible to support the accuracy of note-taking by allowing us to listen again to what was said.
- Notes, including quotes, were added to an online template to support analysis.
- Key themes across the interview data were identified. The frequency with which they were mentioned as well as their importance in structuring participant accounts of their experiences helped us identify the key themes to report.

3. Findings

The findings in this section are intended to offer insight into the views and experiences of patients from minority ethnic groups in Scotland. We have used bold text for direct quotes to share participant's experiences in their own words. Our findings are based on highly

focussed engagement and should offer direction for improvement and further exploration only. The findings complement and offer additional insight in respect of existing studies about the experiences of patients from minority ethnic groups. The specific findings of this engagement should not be generalised.

Participants reported using a wide range of NHS Scotland services. These included: GP surgeries, hospital outpatient services, accident and emergency, mental health services, maternity services, pharmacy services, dental surgeries and the Scottish Ambulance service. While all participants talked about their personal experiences, three participants additionally shared their experiences of accessing NHS services on behalf of their children.

3.1 Communication

Interview participants talked about a variety of issues they had experienced in relation to communication, including with clinicians and administrative staff. Some of the specific themes we captured included things such as understanding treatment, being able to ask questions, accessing appointments and language interpreters, navigating assumptions, being heard and feeling able to consent to proposed treatment. Many of the experiences recounted to us were negative ones, but not all were. As explained above (see 'Approach') we gave participants the opportunity to talk about more than one experience they had over the last few years and the way their experiences were different.

In what follows, we have broken down the broad theme of 'communication' into four related sub-themes: 'understanding treatment,' 'being heard,' 'giving consent' and 'navigating assumptions.' We have chosen these descriptions to explain what participants described themselves as doing when they engaged with NHS services. We have tried to let the participants' voices do the descriptive work. The result however is based on our interpretations and should be read as such. Where we have noticed similarities between the themes discussed and those emerging in some our other engagement activities, we have highlighted them.

3.2 Understanding treatment

Many participants described the challenges they encountered in understanding their treatment. They cited the use of medical terminology and the attitudes of medics as influencing factors. For example, one participant was prescribed hormonal medication without an explanation as to how to take it correctly. They mistakenly believed the medication to be for pain relief and did not follow-up correctly. Another participant said their consultant had used too much medical terminology which they did not understand, and their 'dismissive' approach made it challenging to ask questions. This was similar to another participant who said they had only understood their treatment after a follow-up conversation with a trauma nurse who explained things better. Not understanding has consequences for recovery, with one person's recovery set back weeks because they had not

understood they should receive physiotherapy–this was only picked up after a later visit to the GP.

One obstacle to understanding treatment was a language barrier, where participants did not speak English as a first language. For example, one participant reported that their second language is English and they feel [the GP practice] does not try to understand but rather transfers them to the pharmacy for medicine without giving advice. It is impossible to participate in decision-making around your own care and treatment if you do not have full information. There are additionally safety concerns that become relevant in the case of poorly understood and self-administered medication.

Two participants said they had felt uncomfortable with conditions in the hospital treatment room and found these hard to challenge because of communication challenges and feeling disempowered. In one case, the participant was not asked for her permission to have a student nurse in the consulting room with her. She said that for this appointment she would have rejected the request. Another said that the hospital consultant did not close the curtain completely when asking her to remove her clothes, and she was visible to a male student nurse. In both cases, the participant expressed they had been uncomfortable with the observation but their consent had not been requested.

Some participants described the value of understanding and being able to participate in decisions about their treatment, including through the ability to ask follow-up questions during an appointment. A letter confirming the outcome of an appointment was referred to, but in the context of not being given adequate information upfront. For example, one person said "**[If] I'm told I have [a medical condition], I want this explained to me. I don't want to wait for the letter to come and then wait until my next appointment with the consultant to ask my questions**." This contrasted with someone else's experience of the Accident and Emergency department, which they described as good because they were told what was happening [and] what tests were being done at the time.

Another participant talked about getting support from a family representative. This enabled them to ask to see the medical notes for their child and to source a discharge letter which explained the specific treatments given during the hospital stay. This helped the mother understand what had been wrong with her child, what treatment they had been given and what the next steps were–all information she said had not been delivered in hospital.

Participants suggested factors that they thought could help with their understanding. Sometimes low understanding related to language comprehension, and several participants were keen to highlight the value of language interpreters being available to support appointments. Participants also noted that plain English communication had a significant positive impact, praising staff who had been able to explain things in more understandable

terms. One further suggestion was for NHS staff to chase up missed appointments as they may not have been properly understood by the patient.

3.3 Being heard

A repeated theme raised by participants was their ability to speak with a member of clinical staff, have follow-up questions answered and the extent to which they felt their symptoms had been taken seriously during or before a consultation.

On getting to an appointment in the first instance, participants noted the need to use online booking systems to obtain GP appointments. Many participants had low levels of literacy or were less competent in written English and so found online booking more difficult to understand and work with. Some participants reported this was the only way to obtain an appointment and that phone enquiries would be directed to online booking. Difficulties obtaining appointments for this reason as well as challenges communicating with reception staff could lead to frustrated communications with GP surgeries and a feeling of being dismissed early on. One participant said about their family "t**he GP always turned us away**." Another felt she was treated "**like the angry brown woman**" with GP staff communicating a sense of "**stop annoying us, basically**."

During consultations, participants said they had not always been able to explain themselves and ask questions, within the allotted appointment time. It was clear that the time limit on appointments was a consistent barrier. Time limited appointments seemed to exacerbate situations where communication was challenged in other ways and could add to a sense of being dismissed, For example, one participant commenting on a hospital appointment said "**they seemed to rush through the appointment, and I was told that everything would be explained in the letter. I felt they didn't want to communicate with me because they assumed I didn't understand English**." Another participant cited time as one reason they were unable to obtain all the information they wanted, saying "**I had questions I wanted to ask but there was no opportunity for me to ask them because the appointment was rushed**." While there are systemic constraints around the timings of GPs appointments, the key point to highlight here is the value of medics being prepared to listen and take time to ask questions.

Moreover, participants communicated that that it can be challenging to gain access to the correct treatment pathways. One participant noted "**there's a rumour around [minority ethnic] communities that they [GPs] just don't refer you**." Two participants shared stories of 'near misses' because their health concerns were not properly recognised. For example, one participant was turned away for an on-the-day GP appointment but then managed to book the appointment after seeking help from a staff member at a community organisation. The appointment resulted in an ambulance transfer to hospital due to the seriousness of their condition. Another participant received a cancer diagnosis only after expressing distress that the consulting doctor had not properly investigated their concerns. A second

opinion was pushed for by a doctor who had seen their distress and became uncomfortable with their discharge.

In the latter case, the participant was clear about the difference in approach between the first consultation and the second. They said of the second doctor:

“she spoke with me and asked me questions whereas other doctors did not. She asked me about my symptoms and listened to me. I was talking rather than them telling me. She asked me what symptoms I had, how long I had had symptoms, if I was tired, what’s been happening. She took her time to ask me.”

Similar to the above theme of ‘understanding treatment’ the difference in experience and outcome is made by the time and empathy of medics. Participants felt that being ‘**listened to in the beginning**’ could have the biggest positive impact on their experience. Another reflected that **“with my GP, I don’t have to explain myself and they treat you as a person ... They communicate with me ... I can have a conversation, it doesn’t feel rushed.**”

3.4 Navigating assumptions

Several engagement participants talked about navigating the assumptions of healthcare staff and the frustration this had caused. The main assumptions reported to us were that participants were in receipt of a state benefit or that they had poor comprehension of English. One participant said “**you are stereotyped that you are there to take advantage of everything and you feel put down by this**.” Another said “**even though I speak English well and say that I do, they speak to me in a sign language way, they show with their hands and change the way they speak ...**” This was not always the case however, with established relationships potentially being a protective factor. For example, one participant said “**for appointments at my GP practice, they are less likely to assume that you don’t understand English because they know you. [However] at the hospital, when you go for scans or at the reception desk, they act and treat you like you don’t understand English.**"

Some participants suggested the issue would be helped by staff simply withholding judgement and taking more time to ask questions. The education of NHS staff about racism, including microaggression, was also noted; while some participants felt that community links should be strengthened through local engagement activities to achieve greater understanding between health boards and different groups accessing health and care services. While regular local engagement activities are carried out across the country, some groups may not be accessing opportunities–in particular, a desire for local engagement groups supporting refugees to use their skills and contribute to decision-making was noted.

3.5 Respecting culture and religion

Two participants described experiences relating to the way aspects of their religion or the cultural system they were part of were understood and accommodated when accessing health care. One participant who practices Islam recounted how Muslims are encouraged to wash their face, hands, arms, feet and rinse their mouth and nose before each of the five daily prayers. The participant said “**it is really hard when you're trying to explain to a nurse**

... can I get a bowl of water and they're just not understanding. Why do you want a bowl of water at your bed? Because I just need to pray." Another issue encountered was the food choices during hospital stays and sometimes missing information about whether the food is halal or not.

One participant described their role as a case worker supporting survivors of female genital mutilation (FGM). They said: "a lot of [survivors] don't go for smear tests due to the comments they get from the nurses o*h gosh, how can I get this [speculum] inside you?* ... [and] h*ow do you manage to have a sexual life?*" The participant said that saying this in front of a FGM survivor at their first smear test, can mean they never go back for smear tests. She went on to say patients may not seek gynaecological support "**unless pregnant ... [because] they don't feel respected**."

Again, participants felt there are remedies for these issues such as training for staff with the aim of supporting inclusive practices. Participants thought that overall services need to better understand the cultural aspects to a patient's care and treatment, including how people from different ethnic groups communicate and cope, and be able to use that lived experience insight to shape how services work.

4. Recommendations and what we'll do

This section of the report brings together recommendations drawn from the findings of our engagement exercise, and our conclusions.

Towards the end of our engagement interviews, we asked participants what mattered to them about anti-racism in the NHS. We understand that this question may have felt quite conceptual to some participants and this is reflected by the range of response. Nonetheless, the answers we received to this question included lots of concrete recommendations about how NHS Scotland services could better serve minority ethnic communities and patients. These recommendations broadly track the findings set out above. We have used a combination of our own understanding and the words of our engagement participants to set out the following recommendations:

Recommendation 1: Provide more education for NHS Scotland staff, including more awareness of unconscious bias–"*I don't normally think it is a racism thing. I normally think it's lack of knowledge."*

- **What we'll do:** Healthcare Improvement Scotland's anti-racism plan will include training and development, including for key staff groups who can make a difference in respect of their leadership and decision-making.

Recommendation 2: Drive forward person-centred care that considers the culture and language of the patient. This approach also needs to be carefully applied to people who do not speak English as their first language.

- **What we'll do:** We will share intelligence about the diversity of cultural needs patients may have when planning improvements in person-centred care. We will do this by capturing cultural considerations as part of our Equality Impact Assessments for new work. We will also encourage our staff to undertake the NHS Scotland learning module 'Cultural Humility.'

Recommendation 3: Recruit NHS staff with refugee experience.

- **What we'll do:** As part of Healthcare Improvement Scotland's anti-racism plan, we will commit to increase the number of colleagues with a minority ethnic background in our own workforce and to disrupting bias in recruitment by exploring how we can use more diverse interview panels.

Recommendation 4: Make more language translators available to support patient appointments.

- **What we'll do:** When carrying out community engagement we will identify where language translators can support people to participate; and we will work with our contacts to provide translation as needed. While the provision of interpreters for people receiving health and social care is outside Healthcare Improvement Scotland's remit, we will share awareness with colleagues in the system about where language can be a barrier to accessing services. We will offer improvement support where it feels appropriate and possible for us to do so.

Recommendation 5: Use plain English as far as possible–"*can a diagnosis or treatment recommendation be explained without too much medical terminology?*"

- **What we'll do:** We will continue to promote our policy of producing written information aligned with a reading age of 8 years.

Recommendation 6: Take time to ask patients about their symptoms, build a good understanding and ensure their understanding by answering questions.

- **What we'll do:** Healthcare Improvement Scotland is does not provide clinical services directly to patients and therefore does not have individual clinical care conversations. We can however influence patient-facing services across NHS Scotland by promoting high quality person-centred care in all of our work. Examples of where we do this include:

➢ Excellence in Care Framework

➢ Right Decision Service

➢ What Matters To You

➢ Promoting the Care Experience Improvement Model

- Promoting the use of BRAN questions as well as shared decision-making and improved communication between patients and health professionals: Fourteenth Citizens' Panel report | HIS Engage

Recommendation 7: Ensure that patients from minority ethnic communities know their rights in relation to healthcare.

- **What we'll do:** As part of Healthcare Improvement Scotland's anti-racism plan we will use our community engagement structures to strengthen links with minority ethnic, including refugee communities to ensure that diverse communities better understand their rights and can influence the health and care system. This will include signposting communities to NHS bodies that support communities, for example link with NHS Inform, who have accessible information that covers both rights and responsibilities The Charter of patients rights and responsibilities | NHS inform.

Recommendation 8: Build inclusive NHS cultures by listening to those with lived experiences–*"it will be baby steps but if its heading in the right direction that's something."*

- **What we'll do:** In addition to our staff training and community engagement activity above, we will facilitate a peer support space for staff from minority ethnic backgrounds and convene a regular meeting space for anti-racism collaboration.

Recommendation 9: Encourage and support local engagement structures for refugees to use their skills and contribute to decision-making.

- **What we'll do:** As part of Healthcare Improvement Scotland's anti-racism plan, we will strengthen links with minority ethnic, including refugee, communities.

5. Appendices

Appendix 1

What Matters to You? NHS anti-racism plans

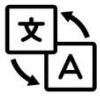
Participant Information Sheet

Please read this information sheet carefully. If you have any questions please get in touch:

Equality Team email: his.equality@nhs.scot

Equality Team phone: 07929025815 / 07929026682

Healthcare Improvement Scotland is committed to inclusive communication. We are happy to consider requests for other languages or formats:



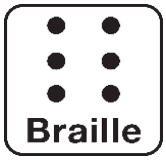
Translation

Easy Read

BSL

Audio

Large print



Braille

We would like to speak to you during October 2024 if:

- You have a minority ethnic background or identity.
- You have used NHS Scotland services in the last three years–at least once between August 2021 and August 2024. For example, this could be visiting your GP, attending a hospital appointment, receiving care in the community or staying in hospital to receive treatment.
- You are happy to talk about your experience using NHS Services as someone with a minority ethnic identity.

All health boards, including Healthcare Improvement Scotland, have been asked by the Scottish Government to develop their own anti-racism plan.

Healthcare Improvement Scotland works to improve the quality of health and care services across Scotland. Anti-racism approaches are essential in improving services for minority ethnic communities. Anti-racism can help address the unfair differences in health and

services that people with minority ethnic backgrounds experience compared to white people.

It is important that our plan is informed by people with minority ethnic backgrounds who use NHS services. Our Community Engagement team is carrying out interviews between 1st October and 8th November.

The interviews will help to:

- highlight what needs to improve for minority ethnic communities accessing NHS Scotland services
- identify where NHS Scotland services are getting it right for minority ethnic communities and how we can build on this
- inform anti-racism actions for Healthcare Improvement Scotland.

We will also share our interview findings with our national partner organisations to help inform their own anti-racism plans. Our national partners are NHS Education for Scotland, NHS National Services Scotland, Public Health Scotland, NHS24, NHS Golden Jubilee University National Hospital, and the National Ambulance Service.

What we will ask you to do:

You will be asked to take part in an interview with a member of our team. The interview can be online via Teams or over the phone. It could also be in person if this is the most accessible option for you.

Each interview will last **30-45 minutes.** We will take some notes and **record the interview** to help us remember what you said.

We will ask you the following questions:

- Please can you let me know if you are speaking as an individual patient or representing a community or group?
- Please tell me about a time you used NHS Scotland services in the last three years
- Can you tell me your thoughts about how fairly you feel you were treated?
- Thinking about your experience as a patient with a minority ethnic background, how well do you feel you were understood and had your needs met?
- Thinking about your experience as a patient with a minority ethnic background, is there anything that would have helped you feel better understood or supported?
- Is there any other experience you have had with NHS Scotland that felt different to this one?
- What matters to you about anti-racism in the NHS?

You can bring notes to help you remember what you want to say.
You can choose to have someone (like a trusted friend or family member) with you. If there is anything you need to be able to participate, please just let us know.

Letting us know you want to take part:
If you would like to take part, please select a time using this online form:

You can also get in touch with us directly by:

- Emailing the Equality Team: his.equality@nhs.scot
- Phoning the Equality Team: 07929025815 (Rosie) or 07929026682 (Jackie)

We will take your name and contact details. We will check you have the information about the project and identify with a minority ethnic background. We will ask about your availability, how you would like to be interviewed and anything you need to help you participate. We will then confirm an interview time with you.

What if you change your mind?
Your participation is voluntary. You can leave the interview at any time. During the interview you can give us as much or as little information as you like.

How we will use your information
We will create a report for Healthcare Improvement Scotland staff and our national partner organisations about the views and experiences shared during interviews. Our report, including your comments, will inform the actions that HIS and our partner boards put into their anti-racism plans.

The report will be published on the Healthcare Improvement Scotland Community Engagement website. We will tell you when the report is available and send you a link.

We may use direct quotes from you in the report. All quotes will be made anonymous and will not include your name or any other information that could identify you. Anonymised quotes, summaries or analysis of your comments or views may be used in the following ways:

- Internal NHS reports
- Presentation materials for NHS education or improvement workshops, conferences or events

We may use your contact details to get in touch with you after the work is completed, to share our report and find out about your experience with our interview process.

To support our work we will hold information relating to you, including:

- Personal details–your name, ethnicity and contact details
- Typed notes summarising the comments and views you have given us
- Audio or video recording of the interview

Equality monitoring information
You can choose to complete an anonymous equality monitoring survey. This will not be linked to your feedback. It will ask you about your age group, gender, religion etc. If you complete the survey you will help us understand the diversity of people we have heard from. You can complete the equality monitoring survey online at this link:
https://www.smartsurvey.co.uk/s/GVAREQM/
You can ask your interviewer to help you if needed.

We will hold records of our engagement with you only for as long as necessary following the conclusion of the project. All information will be held in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You can find out more about how

Healthcare Improvement Scotland use your personal information here:
http://www.healthcareimprovementscotland.org/footernav/respecting_your_privacy.aspx

For our full privacy policy, please go to www.hisengage.scot/privacy.

For more information about how we process your personal data, or if you have a concern, contact our Data Protection Officer at his.informationgovernance@nhs.scot. Alternatively, you have the right to complain to the ICO https://ico.org.uk/concerns/.

Your rights

The Data Controller for this information is: Healthcare Improvement Scotland
Under data protection laws you have the right to be informed of what your information will be used for; access to the information held about you; to rectification if there are any errors in the information held; of erasure; and to withdraw consent.

HIS Data Protection Officer: If you have questions or concerns about how we process your personal data, or if you wish to exercise your rights, email his.ig@nhs.scot

If you would like to know more about how Healthcare Improvement Scotland use and protect your personal information see our privacy notice here:
http://www.healthcareimprovementscotland.org/footernav/respecting_your_privacy.aspx

Appendix 2

Participant Consent Form
Gathering Views–Healthcare Improvement Scotland Anti-racism plan

By ticking the options below you are giving your consent to take part in a Gathering Views discussion.

If you wish to proceed, please confirm the following, verbally or in writing:

1 I have read and understood the information sheet. ☐

2 I have been able to ask questions about this work and am happy with the answers I got. ☐

3 I understand that I can choose whether or not I will take part in this discussion and that I can choose not to answer any question or stop taking part at any time, without having to give a reason. ☐

4 I agree for what I say to be used in reports and publications about this work, but that my name will not be used. I give permission for Healthcare Improvement Scotland to hold relevant personal data about me and I understand that my comments are anonymous. ☐

5 I agree to take part in this work. ☐

Name

Signature
Date

Appendix 3

Suggested introduction:

Why we are collecting this information

In carrying out our work, Healthcare Improvement Scotland has a duty to involve the people who access healthcare. We take this duty seriously because it helps improve the work we do.

We want to make sure that everyone has an equal opportunity to take part, and that we have not overlooked anyone. The following equality monitoring questions help us understand the groups we have heard from and the groups we need to do more to include.

The information you provide is not linked to your name or any other personal details. It will be kept anonymous and only reported in a way that does not identify individuals. You do not have to answer a question if you do not want to.

Suggested questions and answer options.
Please be aware you should only ask for information that is required as part of your work and / or that you have a clear use for. You should be able to explain your purposes clearly to the people you are requesting data from. See comments for additional advice about answer options.

1. **What is your sex?**

Female ☐ Male ☐ Prefer not to say ☐

2. **Do you consider yourself to be trans or have a trans history?**

Trans is a term used to describe people whose gender is not the same as the sex they were registered at birth.

Yes ☐ No ☐ Prefer not to say ☐

3. **Which age group do you belong to?**

Under 16 ☐ 16-25 ☐ 26-35 ☐ 36-45 ☐

46-55 ☐ 56-65 ☐ 66 and over ☐ Prefer not to say ☐

4. **If you are under the age of 26, please can you tell us whether you have ever had any experience of being in care? This can include foster care/supported care, kinship care, residential care, looked after at home (supervision order).**

Yes, I have had experience of being in care ☐ Prefer not to say ☐

No, I have not had experience of being in care ☐ Not applicable ☐

5. **Do you consider yourself to be disabled or to have a long-term health condition?**

(The Equality Act 2010 defines a disability as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. Substantial means the effect is more than minor or trivial and long-term means the condition has lasted or is likely to last 12 months or more).

Yes ☐ No ☐ Prefer not to say ☐

If you answered yes, please give a brief description of your disability or health condition **(optional).**

6. **Do you use British Sign Language (BSL)?**

Yes ☐ No ☐ Prefer not to say ☐

7. **Do you look after, or give any help or support to family members, friends, neighbours or others because of either:**

- **long-term physical / mental ill-health / disability; or**
- **problems related to old age?**

Yes ☐ No ☐ Prefer not to say ☐

8. **Which of the following best describes your sexual orientation?**

Bi / Bisexual ☐ Gay ☐ Lesbian ☐ Heterosexual/straight ☐

Something else. Please write in (optional) _____

Prefer not to say ☐

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9. What is your religion or belief?

Buddhist	☐	Hindu	☐
Christian–Church of Scotland	☐	Jewish	☐
Christian–Roman Catholic	☐	Muslim	☐
Christian–Another denomination	☐	Pagan	☐
Sikh	☐	None	☐

Prefer not to say ☐
Something else. Please write in _____

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10. How do you describe your ethnicity?

African

African, African Scottish or African British ☐ Other, please write in _____

Arab

Arab, Arab Scottish, Arab British ☐ Other, please write in _____

Asian, Asian Scottish, Asian British

Pakistani, Pakistani Scottish or Pakistani British ☐
Indian, Indian Scottish or Indian British ☐
Bangladeshi, Bangladeshi Scottish or Bangladeshi British ☐
Chinese, Chinese Scottish or Chinese British ☐
Other, please write in _____

Black or Caribbean

Black, Black Scottish, Black British ☐
Caribbean, Caribbean Scottish, Caribbean British ☐
Other, please write in _____

Mixed/multiple ethnic groups

Any mixed or multiple ethnic groups ☐

White

Scottish ☐ Other British ☐ Irish ☐ Gypsy/Traveller ☐

Polish ☐ Roma ☐ Showman/Showwoman ☐

Other ethnic group (eg Jewish or Sikh)

Please write in _____

Prefer not to say ☐

11. **Do you usually have enough money each month to pay bills, buy the food, clothing and essentials you need and participate in your community?**

Yes ☐ No ☐ Prefer not to say ☐

12. **Please use this space to tell us anything else you would like us to know about how you identify in relation to any of the above questions.**

You can read and download this document from our website.
We are happy to consider requests for other languages or formats.
Please contact our Equality, Inclusion and Human Rights team on 0141 225 6999 or email his.equality@nhs.scot.

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