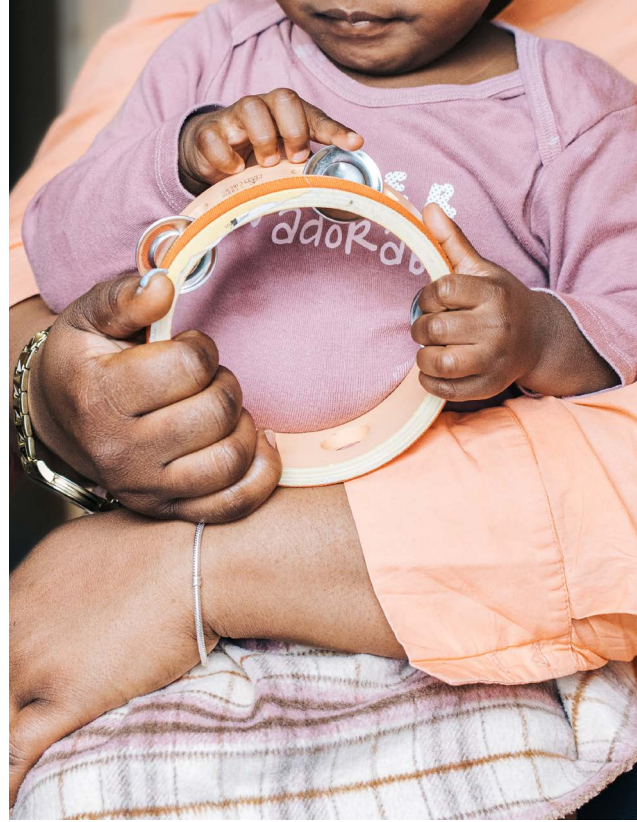**NHS RACE & HEALTH OBSERVATORY**

BRIEFING FROM NHS RHO ROUNDTABLE:

ETHNIC EQUALITY IN RAISING WORRIES AND CONCERNS

This briefing explores the implementation of 'Martha's Rule' and other elements of the Worries and Concern programme. With these interventions designed to make it easier for staff, patients, and families to raise their concerns, we convened a roundtable to explore how this might impact ethnic minority communities.

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INTRODUCTION

In the NHS, there is a growing appreciation that avoidable harm in healthcare is disproportionately experienced by patients from Black and Minority Ethnic backgrounds. Patient safety incidents, such as perioperative pulmonary emboli and adverse drug events, occur at a higher rate in Black patients compared with White patients[1]. Considering inequitable health outcomes as the result of poor patient safety practice can enable us to interrogate the role that healthcare itself plays in driving health inequalities, and as a result, how we can redress them. There is, therefore, a clear need to view patient safety failures through the lens of structural racism. Over the past three years, the NHS Race and Health Observatory (RHO) has contributed to a growing body of evidence highlighting the inequity experienced by ethnic minority communities, including evidence indicating that poor communication from healthcare professionals, and experiences of being dismissed in healthcare interactions, are actively contributing to ethnic health inequalities.

NHS England took a strategic approach to design, develop and deliver a National Worry and Concern Improvement Collaborative ('the Collaborative') with two aims:

Aim One

To test, implement and evaluate a reliable method for patients (or their families/carers) to escalate worries and concerns about acute illness/ deterioration.

Aim Two

To test, implement and evaluate reliable methods for patients (or their families/carers) to routinely input their views about their illness and any worries and concerns into the health record.

Seven acute NHS trusts participated in the Collaborative from April 2023 to April 2024. Implementation of the aims involved catalysing two changes: contributing to a shift in culture and practice that empowers patients/families/carers to speak up about deterioration and the systematic incorporation of patient worry and concern into early warning and diagnostic tools.

As part of the National Worry and Concern Improvement Collaborative, national leads from NHS England partnered with the NHS Race and Health Observatory to advance work aimed to address ethnic health inequalities related to patients, families, and carers raising their worries and concerns when in acute illness or deterioration. The NHS Race and Health Observatory facilitated a national roundtable event in May 2024 which was attended by a broad range of stakeholders and sought to understand how patient safety initiatives that support patients at risk to raise concerns in relation to acute deterioration and illness, may need to be adapted for ethnic minority communities, and what considerations need to be in place to ensure the benefits are equitable for all.

Whilst the implementation of patient safety initiatives such as the National Worries and Concerns Collaborative and Martha's Rule signal a positive shift in the embedding of patient and family voices into one's care, the roundtable aimed to identify actionable insights that ensure ethnic minorities have their worries and concerns heard and acted upon in a timely manner. This briefing note provides reflections and recommendations from the roundtable, targeted at patients, policy makers and provider organisations to support the implementation of patient safety interventions aimed at enhancing patient and family voice and agency around concerns.

MARTHA'S RULE

Martha Mills died in 2021 after developing sepsis, following an admission with a pancreatic injury after falling off her bike. The coroner ruled that Martha would have survived had she been moved to intensive care earlier as Martha's mother had explicitly raised concerns about sepsis, but these were not responded to promptly. Following her death, Martha's family successfully campaigned for the introduction of 'Martha's Rule'.

In response to Martha's case, and many others like it, the Secretary of State commissioned a rapid piece of policy work by the Patient Safety Commissioner (PSC), Henrietta Hughes, to consider how a national call for rapid response service for concern could be successfully implemented across the NHS in England.

In April 2024, NHS England introduced Martha's Rule which gives acutely ill and deteriorating patients, and their families and carers who are concerned about their care, an independent pathway with 24/7 access to a rapid review from separate critical care team.

The 3 components of Martha's Rule are:

1.
All **staff** in NHS trusts must have **24/7 access to a rapid review from a critical care outreach team**, who they can contact should they have concerns about a patient.

2.
All **patients, their families, carers, and advocates** must also have access to the same 24/7 rapid review from a critical care outreach team, which they can **contact via mechanisms advertised around the hospital**, and more widely if they are worried about the patient's condition.

3.
The NHS must implement a **structured approach to obtain information relating to a patient's condition directly from patients and their families at least daily**. In the first instance, this will cover all inpatients in acute and specialist trusts.

It was announced in May 2024 that the initiative is set to be rolled out across 143 hospitals, the first phase of which will provide participating provider sites which already offer critical care outreach with access to government funding to produce posters and leaflets to inform patients of the support available to them.

> We cannot ignore evidence that shows how **harm is unequally** and **disproportionately experienced by minority ethnic communities.**

This initiative is part of a broader work programme by NHS England which seeks to reduce the harm caused by deterioration, which builds upon NHS England's Worry and Concern Improvement Collaborative and emerging evidence that the integration and communication of patient worry, and concern has huge potential to improve the care of patients at risk of deterioration.

Whilst these measures signal a positive shift in embedding patient voice in care, we cannot ignore evidence that shows how harm is unequally and disproportionately experienced by minority ethnic communities in the UK healthcare system. Introducing patient safety measures such as Martha's Rule may only serve to give greater agency to those who already have it within the system and fail to protect the most marginalised in society. The question the RHO seeks to interrogate is how such measures can be applied equitably to ensure **all** patients and families are equally empowered.

ROUNDTABLE DISCUSSION

The national roundtable, held in May 2024, was attended by experts and stakeholders across the health and care sector (full list available in Annex A). This section of the briefing distils the discussions from the roundtable, where we explored the following questions:

- What do barriers to raising worries and concerns around acute illness and deterioration look like specifically for patients, families and carers from ethnic minority backgrounds?

- What does good look like – what are examples of how the barriers we have identified have been successfully overcome?

- How might people from ethnic minority backgrounds be enabled to document an assessment of their wellness or illness into the health record, at least daily?

- How can organisations incorporate learning from people with lived experience of racism and discrimination to make escalating and documenting worries and concerns equitable?

- What would key messages for patients, carers and families from ethnic minority backgrounds be?

Discussions ranged from the impact of racism, an awareness of cultural sensitivities, the role of language, how it relates to the NHS workforce, as well as the need for co-production and data collection. The points below reflect the views expressed on the day.

We have framed actionable insights from the discussion around the **RHO Anti-Racism Principles.**

1. **Demonstrate leadership by naming racism**, engaging seriously and continuously with the ways in which racism impacts the lives of the patients and the public, and actively working to dismantle it.

2. **Understand and acknowledge** that structural, institutional and interpersonal racism all impact on health and be clear about where accountability lies for improvement and progress. Create transparent pathways for raising concerns and tangible steps for addressing them.

3. **Meaningfully involve racially minoritised individuals and communities** in in every stage of developing a service or intervention, including ensuring that teams and decision-making structures themselves are racially diverse and fundamentally inclusive.

4. **Collect and publish data** on race inequity in its entirety, ensuring it directly informs policy, strategy, and improvement. Where data is not available, change policies to ensure that data is collected.

5. **Identify racist bias** in policies, decision making processes, and other areas within your organisation.

6. **Apply a race-critical lens** to the adoption of any interventions or improvements to be tested, and to the design and delivery of services.

7. **Evaluate and reflect** on interventions using metrics that recognise the role of racism as determinant of health. These evaluations should seek to understand the extent to which interventions mitigate the impacts of racism.

IMPACT OF RACISM

Attendees discussed the fact that racism and implicit bias continue to exacerbate ethnic disparities, where Black, Asian, and ethnic minority communities have poor access, experience, and outcomes across the healthcare system. This is compounded by a disproportionate lack of acknowledgement of their concerns, with patients from marginalised communities routinely experiencing their worries being ignored or dismissed. For example, the Observatory's Rapid Evidence Review found that within maternal and neonatal care '*poor active listening skills among healthcare providers undermined communication and left women feeling uninvolved, dismissed and unsafe*' reducing their ability to make informed choices and affecting their overall care.

Much of this stems from racist stereotypes and medical myths which can often lead to differential care. The APPG for Sickle Cell and Thalassemia published a report in 2021 which highlighted how racial inequality was a defining factor in sickle cell care, with some doctors denying Black sickle cell patients pain relief due to the misconception that Black people experience less pain than White people.[2]

This pervasive false belief about biological difference is reflected in Black patients' treatment and assessment of risk. Frequent experiences of being stereotyped or not believed can lead to ethnic minority patients to become disengaged with healthcare system and can in turn have a real impact on individual's ability to meaningfully advocate for themselves. Healthcare workers need to acknowledge their biases, whether conscious or unconscious, and proactively engage with the patient to ensure a fair opportunity to raise their worries or concerns.

> Healthcare workers **need to acknowledge** their **biases,** whether **conscious or unconscious.**

Demonstrate leadership by naming racism: leaders at all levels of the organisation acknowledging the impact of racism on health and taking accountability to work actively to dismantle it. This can include health care practitioners and organisations influencing healthcare towards equity by routinely critically examining how their own biases, attitudes, assumptions, stereotypes and prejudices may affect the quality of care provided. Additionally, leaders should acknowledge that existing hierarchies and culture may make some staff reticent to raise concerns. Leaders at all levels of the organisation should ensure that there are transparent pathways for all staff to raise concerns about patient deterioration, as well as tangible steps for addressing these.

CULTURAL DIFFERENCES AND AUTHORITY

Attendees discussed the fact that racism A consistent theme in the discussion was the cultural sensitives around questioning authority that exist within Black and minority ethnic communities. Clinical spaces can often feel like hierarchical environments which can make families uncomfortable with raising their concerns, which may be exacerbated by a reticence to 'trouble' staff who are already visibly busy or over-burdened. Organisations should support communities where deference to trained professionals is common to engage with the principles of Martha's Rule through culturally sensitive practice (see section on coproduction). It is especially important that, in doing so, organisations do not inadvertently place the responsibility for overcoming these systemic barriers on the communities who are affected by them.

Furthermore, it was noted that due to inequitable experience of care (as alluded to under the section on the *impact of racism*), there is a fear of backlash if patients were to 'complain' or question their care, and that families would hesitate to raise concerns for fear of prejudicing the care their relatives were receiving. A member pointed to early work in Bradford which seemed to suggest that regular collection of responses to consistent questions supports more objective interpretation of the information patients, families and carers are sharing, bypassing potential cultural blockers and allowing for the right care.

Acknowledge that racism in all forms, structural, institutional and interpersonal all impact on health and be clear about where accountability lies for improvement and progress, including by creating transparent pathways for raising concerns and tangible steps for addressing them.well as tangible steps for addressing these.

LANGUAGE

A key component for the successful implementation of patient safety initiatives such as Martha's Rule will include ensuring that the language, and the way in which information related to mechanisms for patients and families to escalate their worries and concerns in relation to acute illness and deterioration is communicated and accessible to all. Trusts will need to ensure that the concepts they're trying to embed make sense to patients from a range of backgrounds and cultures, and that the language used to describe the principles of the rule resonate with the populations they serve. It is important that these resources are codesigned with patients and families that represent the diverse populations of their local areas.

It is crucial that there are adequate translation and interpretation services to hand so that patients and their families can articulate their concerns effectively. Whilst there may be a role for digital translation

Involve racially minoritised individuals at every stage of development and implementation.

services, trusts must consider that such software can be insufficient, missing nuances within certain languages and could therefore cause more harm than good. There was a general preference in the group for the use of more in person, and high-quality translation services.

Furthermore, when describing initiatives such as Martha's Rule, healthcare organisations may want to consider varied ways of articulating its aims. Roundtable participants noted that the word 'concern' might be interpreted by some as a 'complaint' and suggested that trusts engage with local voluntary and community sector organisations to understand what representatives of local populations understood by the terms 'worry' and 'concern', and which, if any, phrases might resonate most effectively with these populations.

Suggestions for accessible outputs include a key words leaflet, and an outline of the initiative in plain English or an easy read format. Whilst it will not be possible to make everyone health literate, there will be an important role for advocates and community leaders to better enable this process by surfacing and addressing misconceptions around what raising a concern means and providing a better understanding of the systems available.

Involve racially minoritised individuals at every stage of development and implementation. Provider organisations can build trusted relationships with communities and community organisations by creating an environment where input is demonstrably valued and acted upon.

WORKFORCE

As the NHS Constitution states, the NHS is a universal service, available to all equally. Roundtable participants took this to imply the need for a culture of equity and respect necessary for ethnic minority communities to have their voices embedded within the system, and for their concerns are listened to. However, the inequalities in access, experience, and outcome between Black and minority ethnic groups compared to their White counterparts demonstrate a failure to actualise this commitment.

Healthcare staff will need to reflect on what person-centred care means, adopting approaches that prioritise active listening and cultural humility, recognising physical power dynamics in the room (e.g. the relative positions of the patient and clinician, and the impact of a person being in uniform), if they are to properly understand patients concerns. However, it would be remiss to not interrogate whether staff themselves feel able to escalate their patients' concerns within the systems they work in. The RHO's rapid evidence review found that ethnic minority staff in the NHS often endured covert and overt discrimination by other staff, causing them to feel undermined and distressed. It is therefore difficult to encourage staff to speak up and challenge harmful practice if they themselves fear repercussions. Trusts and healthcare leaders are encouraged to consider their staff survey results and work to redress these issues by better enabling their ethnic

minority staff to have agency at work. Whilst duty of candour is a legal duty that NHS staff must uphold, it was acknowledged that the NHS workforce crisis will also influence staff's ability to meaningfully connect with their patients in distress. The NHS is unable to keep up with the increasing demand with an estimated 112,000 vacancies, leading to overwhelmed and burned-out staff who have less time to devote to each individual patient. Furthermore, it was noted that hospitals that are better staffed, and where clinicians are better supported, are more able to uphold duty of candour when compared across the system. Roundtable participants suggested a need for organisations to model and practice compassionate care for staff to enable staff to care compassionately for patients.

Organisations can enable accountability for equitable practice by ensuring that there are transparent, secure pathways for staff to raise concerns.

COPRODUCTION

Any patient safety initiatives implemented by providers or policy makers should be codesigned and coproduced with staff and the local community to ensure that there are no unintended inequitable consequences in the delivery of the initiative. Much of this can be done through established community and faith leaders

who already hold people's confidence and can facilitate a full engagement process in a familiar environment. Participants in the roundtable suggested that for people with low levels of confidence in the health system, or low levels of health literacy, clear information was needed to support communities to understand what to expect, what their rights are; and who to approach. Ideally, this information would be made available in advance of deterioration. Apply a race-critical lens to the adoption and delivery of initiatives and services through actively inclusive design and decision-making.

DATA

It was noted at several points that data collection was necessary to help properly understand whether patients or families from diverse communities were using any of the available mechanisms to escalate their worries and concerns. Suggestions included a national collection of data for the implementation of Matha's Rule which can be analysed to understand it's success at engaging ethnic minorities, and an accessible place for people to report their concerns separate to informing their healthcare practitioner.

For the data analysis to be useful, there was also a recommendation of mandatory ethnicity data collection for raising concerns. However, this was caveated with an awareness that many communities are still fearful that sharing their ethnicity will impact on the care they receive. Evaluation of the scheme should include a focus on understanding measures that mitigate the health impacts of racism as well as measures that identify inequalities.

KEY TAKEAWAYS FOR:

The above discussion highlights the importance of race and ethnicity in the implementation of Martha's Rule and other elements of the Worry and Concern programme. Below, we've drawn out specific takeaways for patients, providers, and policymakers, aiming to ensure that these important interventions help to reduce ethnic health inequities in the service.

PATIENTS FROM BLACK, ASIAN AND ETHNIC MINORITY COMMUNITIES

Patient safety initiatives such as Martha's Rule exist to empower and enable patients to be heard and more involved in their care. We recommend that patients and families familiarise themselves with the avenues available to advocate and raise any concerns. This includes checking whether your local hospital is signed up to implement phase one of Martha's Rule.

The link to the participating hospitals can be found here.

NHS PROVIDERS

We recommend that any Trust implementing a patient safety initiatives such as patient and family response systems or Martha's Rule should be co-producing communication materials with the local community in a culturally competent way to ensure relevance and practicality. Additionally, trusts should reference and build on learning from the National Worry and Concern Collaborative. This could include:

1. Working with established community and faith leaders who already hold people's confidence and can facilitate a full engagement process in a familiar environment

2. Building trusted relationships with community organisations, and wider communities, by creating an environment where input is valued and visibly acted upon.

3. Working with community organisations to identify culturally appropriate ways to articulate the principles of Martha's Rule, mindful that some communities may not immediately identify the initiative as relevant to them.

NHS PROVIDERS
(CONT'D)

4. Working with community organisations to identify phrases around 'worry' and 'concern' resonate most effectively with populations

5. Working with community organisations and representatives to develop and share clear information, in advance of deterioration, about what rights patients and families have, what they should expect and who to approach when in hospital.

6. Communications outputs could include key words leaflets, an outline of the initiative in plain English or an easy-read format, all of which should be co-designed with service users and representative of local population diversity

7. Making adequate translation and interpretation services available, so that patients and families can articulate their concerns effectively

Staff should also be trained and feel confident to pick up cues when a patient or family member raises a concern. We encourage hospitals to embed training and practice around cultural sensitivity to ensure that patients feel heard, without compromising one's professional judgement.

1. Leaders at all levels of organisations should be, and hold each other, accountable for actively promoting and modelling equity of care

2. Staff should be supported to reflect on their own biases and assumptions and how they impact on delivery of person-centred care for patients.

3. All staff should prioritise active listening, cultural humility, and recognise the power dynamics at play, to properly understand patients concerns

4. Organisational processes and interactions should demonstrate and practice compassionate care for staff to enable staff to care compassionately for patients

POLICYMAKERS

The development of any patient safety initiative should be done with a clear understanding of ethnic inequalities that persist and should therefore be co-produced with a diverse community.

Evaluation of the scheme should include a focus on understanding measures that mitigate the health impacts of racism as well as measures that identify inequalities. We recommend that the evaluation of Martha's Rule is conducted by a diverse team, incorporates patient voice throughout and builds on the insights, learning and evaluation from the National Worry and Concern Collaborative.

We also suggest that mandatory collection of ethnicity data in the NHS would better support the evaluation and analysis of patient safety initiatives.

FOOTNOTES

1 [Global report on health equity for persons with disabilities (who.int)](), The role of patient safety in health inequalities

2 [RHO-Rapid-Review-Final-Report_.pdf (nhsrho.org)](), pg10

3 [No-Ones-Listening-Final.pdf (sicklecellsociety.org)]() pg.37

ANNEX A
FULL LIST OF ROUNDTABLE ATTENDEES

Kadra Abdinasir	Associate Director for Policy	Centre for Mental Health
Angelie Balalingam	Senior Research and Policy Officer	NHS Race & Health Observatory
Rachel Boardman	Nurse	Nottingham University Hospitals Trust & Nottingham Children's Hospital
Chrstine Ekechi	Consultant Obstetrician and Gynaecologist	Co-Chair RCOG Race Equality Taskforce, Queen Charlotte's and Chelsea Hospital, Imperial College
Ngozi Edi-Osagie	Clinical Director for Neonatal Care	Yorkshire and Humber Patient Safety Research Collaboration
Muhammad Faisal	Assistant Professor in Biostatistics and Lead Statisticians	Yorkshire and Humber PSRC
Aidan Fowler	National Director for Patient Safety	NHS England
Sophie Hadfield	Deputy Director of Nursing	Kings College Hospital NHS Foundation Trust
Laura Hailes	Senior Improvement Manager for the National Managing Deterioration Safety Improvement Programme	NHS England
Taofikat Jimoh-Uthman	Evidence and Evaluation Lead	NHS England
Marsha Jones	Director of Nursing and Safeguarding	North East London ICB
Ngozi Kalu	Assistant Director of Research and Evidence	NHS Race & Health Observatory
Takawira Marufu	Clinical Academic Lead Nursing Research	Nottingham Children's Hospital
Zarah Mowhabuth	Transformation Manager	NHS Race & Health Observatory
Jane Murkin	Deputy Director Safety & Improvement – Nursing Quality, Safety, Improvement, Transformation and Sustainability Directorate	NHS England
Jane Murkin	Deputy Director Safety and Quality - Nursing)	Patient Safety Team
Habib Naqvi	Chief Executive	NHS Race & Health Observatory
Rose Obianwu	Assistant Director of Communications	NHS Race & Health Observatory

Wendy Olayiwola	National Maternity Lead for Equality	NHS England
Angela Osei	Associate Director - Implementation and Adoption	NICE
Louisa Regan	Implementation Support Manager National Implementation Team	NICE
Nandi Simpson	Director - Implementation	NHS Race & Health Observatory
Sarah Tade	GP Registrar	NHS
John Welch	National Clinical Advisor, Acute Deterioration	UCLH