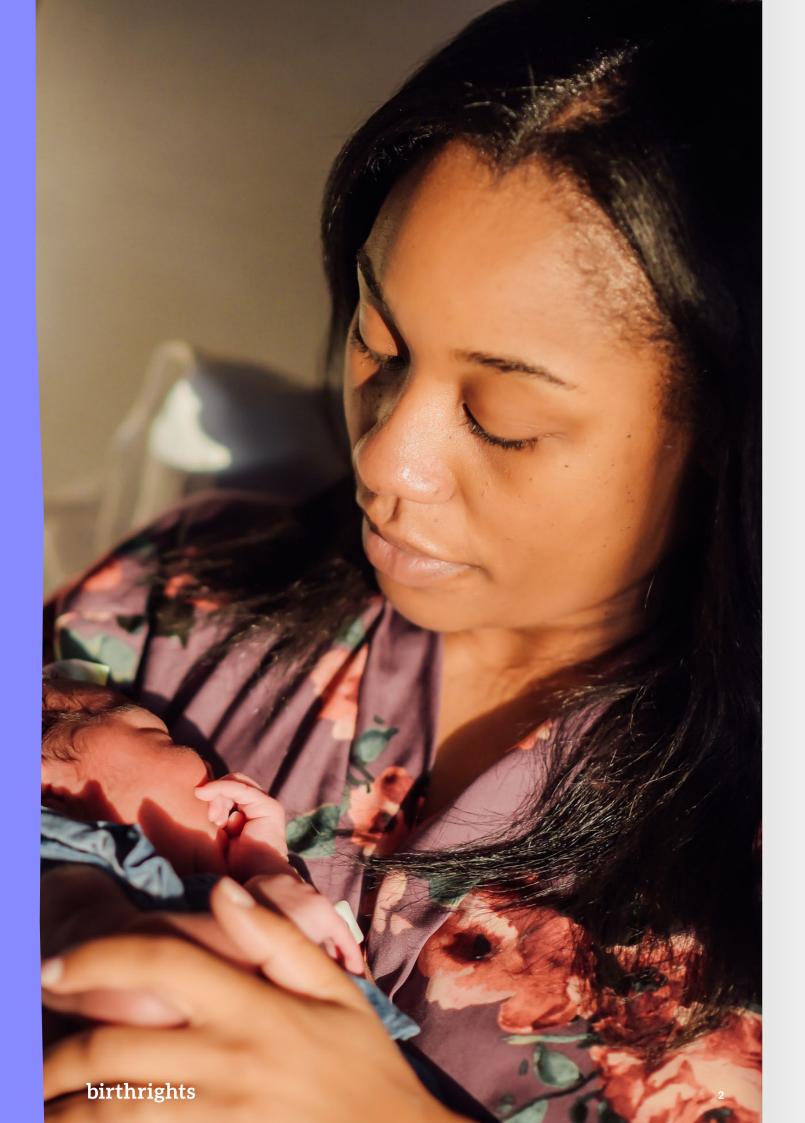
Protecting human rights in childbirth

# Systemic racism, not broken bodies

An inquiry into racial injustice and human rights in UK maternity care





#### Foreword from Shaheen Rahman QC

#### **Chair of the Inquiry**



Black women in the UK are four times more likely to die in pregnancy and childbirth than white women; Asian and mixed race women twice as likely. This glaring inequity is nothing new – ethnic disparities in maternal mortality rates have been published since the early 2000s, but little has changed.

Against this background, I was honoured to be asked by Birthrights to chair the evidence sessions which have fed into its inquiry and now to write the foreword to this important report.

#### The evidence sessions

Birthrights brought together experts with lived experience, healthcare professionals, lawyers and academics to examine how race discrimination impacts upon maternity care. There was impressive engagement by professional, clinical and research bodies, who responded to robust questioning from the panel, for instance on the controversial proposal by the National Institute for Health and Clinical Excellence to recommend induction of labour for all ethnic minority women at 39 weeks. Another example was the Nursing and Midwifery Council's review of a high profile fitness to practise case involving racist abuse, prompting exploration of the need for explicit reference to anti-racism within professional standards.

#### The women who died

Of particular importance was MBRRACE-UK's evidence about ethnic disparities in maternal mortality cases, through an analysis of the clinical records. There were no major differences in the causes of death. But there were disparities in the quality of care. A lack of nuanced care was

particularly notable amongst Black women who died; microaggressions were most prominent in the care of Asian women who died.

#### The report

To this, Birthrights have added compelling detail through the accounts of those who responded to its call for evidence. I pay tribute to all those, particularly those who relived and shared painful experiences, who contributed in this way. Their testimony speaks for itself. Recurring themes are: concerns being dismissed; complaints of pain being ignored due to racial stereotyping; failures to identify sepsis and jaundice in those with darker skin tones; some cases of catastrophic injuries and near misses; a toxic culture of racism and discrimination affecting the lives of those providing care.

This report also provides an essential summary of existing research on racial inequities in birth outcomes and experiences. It examines and illuminates the issues through the lens of human rights law and the landmark case of Montgomery v Lanarkshire Health Board, calling for safe, patient-focussed and respectful care that is free from racial stereotyping and a "white default".

#### The bottom line

There is nothing "wrong" with Black or Brown bodies that can explain away the disparities in maternal mortality rates, outcomes and experiences. What is required now is a determined focus on individualised, rights-respecting care. I look forward to seeing how Birthrights will work with maternity stakeholders to advocate for the calls to action and hold the system to account.

#### Foreword by Sandra Igwe Inquiry Co-Chair



Foreword by Benash Nazmeen Inquiry Co-Chair



Black women in the UK experience horrifying poor maternal health outcomes, which still strikes a personal chord with me, as my birthing experience and postnatal period remains one of the hardest moments of my life.

The inquiry highlights that Black and Brown women do not feel safe when accessing maternity care. The statistics surrounding Black mothers not receiving care cannot be adequately addressed without first understanding, then dismantling, racism and bias in the healthcare system.

Structural racism and issues surrounding Black women accessing care had a massive impact on my journey. The UK system is structured such that public policies, institutional practices and cultural representations work to reinforce and perpetuate racial inequity.

Like many other Black women whose experiences are highlighted in the inquiry, I was stereotyped and felt like I had to suffer in silence after repeatedly raising concerns, then being ignored – just for my words to be carelessly taken out of context, to be judged and shown no empathy, which led me to struggle with the psychological trauma as a result.

My concerns have been echoed by multiple Black women within the inquiry. Actionable change is needed now – and this report is a springboard in the right direction for practical solutions to support better outcomes for Black and Brown women in the UK.

Policies influence change to improve outcomes, but without supporting research, reports and evidence, that change is a long way away. This report shares experiences highlighting racism and systemic biases. Failures to acknowledge and address this have led to an unsafe spaces in these services.

I was once told that the data and poor outcomes we see for Black and Asian women, babies and birthing people can be explained away due to socio-economic deprivation and co-morbidities.

By accepting the first explanation, unchallenged and un-explored, we fail to adequately train staff, we fail to guide organisations to prioritise anti-racism frameworks, and most of all we fail the public we care for.

These failures have led to an added factor that affects care, in this case the impact of racism and bias, both individual and systemic.

Some professionals struggle to see the link between racism and the poor outcomes highlighted by MBRRACE. To them I say...

it is "the straw that broke the camel's back".

If we can actively work towards removing a factor, this factor, we can hope reduce the risk and the burden.

After all, when you start to make improvements for the most vulnerable and marginalised groups, improvements can be seen across all groups.

I hope to see this in my lifetime.

#### **Acknowledgements**

Birthrights would like to thank everyone who has contributed to the inquiry. First and foremost, we are grateful to the hundreds of Black, Brown and Mixed ethnicity women, birthing people and healthcare professionals who shared their experiences of maternity care, in order to make a change and help others. We know this was often distressing and re-traumatising, and we hope we have done justice to your stories.

We are equally grateful to the midwives who engaged with focus groups or interviews and to healthcare professionals up and down the UK who are currently striving to provide safe, inclusive and rights-respecting care.

We could not have done this inquiry without the incredible leadership, support, advice and challenge from our Chair, Co-Chairs and the whole expert panel.

We are also grateful to Pamela Abiola for her initial scoping, evidence review and comms support; to Ese-Roghene Agambi, who helped us design a trauma-informed approach to evidence-gathering; to Adelaide Harris for delivering interviews with LGBTQ+ birthing people; and to Nova Reid for her generous wisdom, expertise and robust challenge, which rooted this work in anti-racist principles and practice. We could not have reached so many women and birthing people without support from our fellow charities and community organisations, who helped to recruit and co-facilitate focus groups: the Happy Baby Community, the Raham Project, the Swansea Women's Asylum Seeker and Refugee Group, the African Community Centre, the Latin American and Iberian Association and Leeds NHS Trust Maternity Voices Partnership.

Thank you also to Emily Robertson from the Ethnic Minorities and Youth Support Team in Wales, and to Amma Birth Companions in Scotland, for their advice, input and connections.

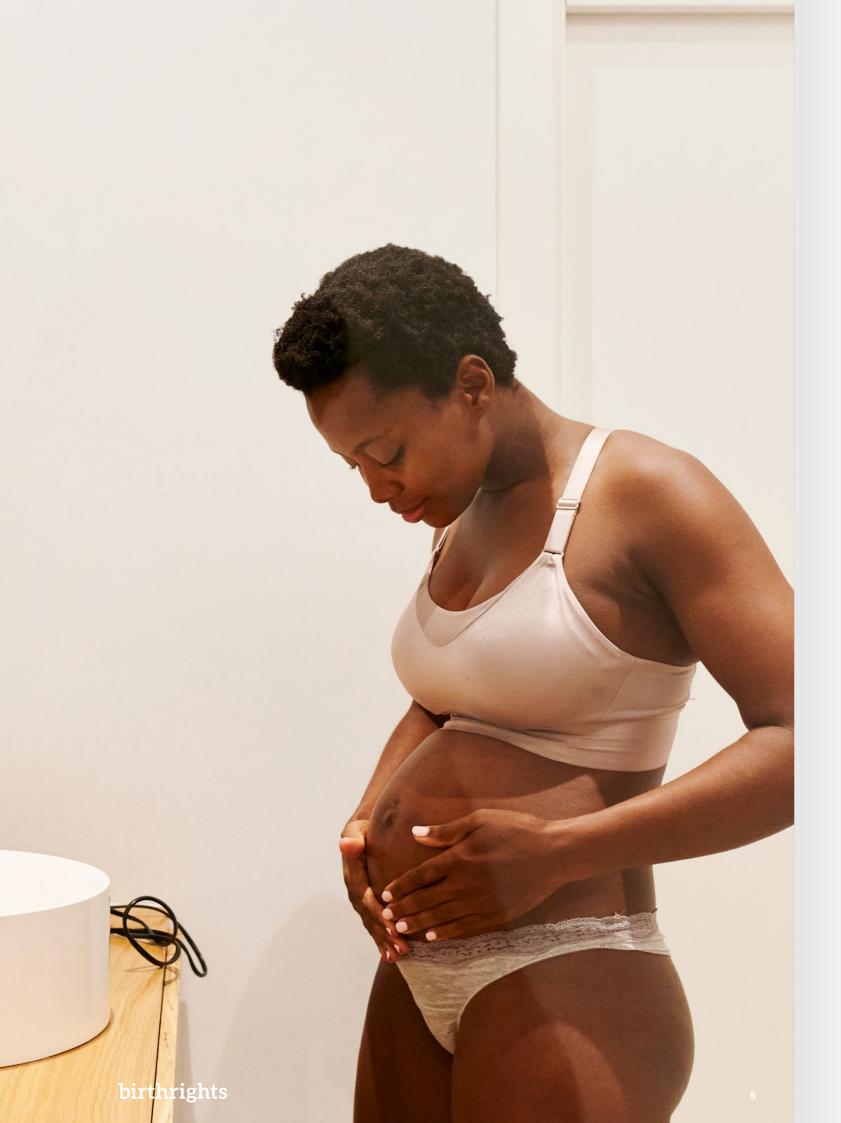
Thank you to all the witnesses at our oral evidence sessions: from Maternity Action, MBRRACE-UK, the National Institute for Clinical Excellence, the Nursing and Midwifery Council, the Royal College of Midwives, and the Royal College of Obstetricians and Gynaecologists.

This inquiry would not have been possible without support from John Ellerman Foundation, Joseph Rowntree Charitable Trust and particularly law firm Leigh Day, who backed and sponsored the idea from the outset. Huge thanks to their solicitors Ceilidh Robertson, Firdous Ibrahim and Lucy MacBrayne for being part of the inquiry's secretariat.

Finally, we would like to pay tribute to the exceptional Birthrights staff team for their hard work – particularly to Melissa Brown for her dedicated and skilful leadership of the evidence-gathering, participation activity, analysis and reportwriting. We are all very proud of this report and hope it drives urgent and meaningful anti-racist action throughout all levels of maternity care.

Thank you to our partner





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# 1. Introduction

"One of the things that's really embedded in this system is the blame that's put on Black bodies and that this is somehow our fault because our bodies don't work in the correct way."

- Midwife, healthcare professional focus group

The 2018 MBRRACE report gave us the stark findings that Black women were five times and Asian women two times more likely to die in the perinatal period than white women<sup>1</sup>. Research has shown similar trends for decades, with Black, Asian and Mixed ethnicity women also more likely to experience baby loss, become seriously ill and have worse experiences of care in pregnancy and childbirth, compared to white women. But for too long, explanations for racial inequities in maternal outcomes have focussed on Black and Brown bodies as the problem - regarding them as 'defective', 'other', and a risk to be managed.

The starting point for our year-long inquiry was that systemic racism exists in the UK and in public services. We set out to understand how it manifests within maternity care and to drive action to end it. This report uncovers the stories behind the statistics and demonstrates that it is racism, not broken bodies, that is at the root of many inequities in maternity outcomes and experiences. We believe this is an urgent human rights issue and urgent action must be taken to address it.

The inquiry heard testimony from women, birthing people, healthcare professionals and lawyers outlining how systemic racism within maternity care – from individual interactions and workforce culture through to curriculums and policies – can have a deep and devastating impact on basic rights in childbirth. This jeopardises Black and Brown women and birthing people's safety, dignity, choice, autonomy and equality.

Led by an expert panel bringing together lived experience with maternity care and legal knowledge, the inquiry reviewed indepth testimony from over 300 people via an online call for evidence, focus groups and interviews. We heard oral evidence from professional and clinical bodies, experts in maternal mortality and antiracism, and other charities who work with LGBTQ+ birthing people of colour and refugee, asylum-seeking and migrant women.

<sup>&</sup>lt;sup>1</sup> MBRRACE-UK, 2018, Saving Lives, Improving Mothers' Care 2018: Lay Summary

#### 1. Introduction

#### Common themes emerged from across the evidence. They are:

- Lack of physical and psychological safety
- Being ignored and disbelieved
- Racism by caregivers
- Dehumanisation
- Lack of choice, consent and coercion
- Structural barriers
- Workforce representation and culture

**Chapter 4** sets out the findings and evidence for each of these themes, including what we heard about good practice in providing inclusive, culturally safe and rights-respecting maternity care.

It is clear that we need urgent action at all levels. We welcome the recent focus on maternal health disparities and the impact on the human rights of Black and ethnic minority groups, as highlighted in the Joint Committee on Human Rights report Black people, Racism and Human Rights,<sup>2</sup> but Government and NHS initiatives must recognise the role that racism plays in the worst outcomes and experiences for Black, Brown and Mixed ethnicity women and birthing people.

#### Our report sets out five calls to action to drive forward concrete change.

#### We call on all parts of the maternity system to:

- Commit to be an anti-racist organisation
- · Decolonise maternity curriculums and quidance
- Make Black and Brown women and birthing people decision-makers in their care and the wider maternity system
- Create safe, inclusive workforce cultures
- Dismantle structural barriers to racial equity through national policy change

#### **Definitions**

#### Women and birthing people:

Birthrights uses inclusive language to reflect the experiences and rights of everyone who may access maternity care - women, trans men and non-binary people. As such, we use both 'women' and 'birthing people' in our work. Most of the inquiry participants were women, so in some cases we use only 'woman' or 'women' for accuracy.

#### Black, Brown and Mixed ethnicity:

The categories in the table below are based on the Census. We were explicit in the inquiry call for evidence that we wanted to hear from people that identify as Black, Brown or Mixed ethnicity that are not specified in these categories, e.g. Somali, Thai, Vietnamese, Mixed: Black and Asian; and from people who may identify primarily by their faith e.g. Black, Asian and Arab Muslims.

Black or Black British	Asian or Asian British	Mixed ethnicity	Other ethnicity
African	Indian	White and Black Caribbean	Arab, Kurdish
Caribbean	Pakistani	White and	
Any other Black African	Bangladeshi	Black African	
or Caribbean background	Chinese	White and Asian	
	Any other Asian background	Any other mixed or multiple background e.g. Black and Asian	

On the advice of the expert panel, we use 'Black and Brown' when speaking about broader groups, rather than 'people of colour' or 'BAME'.

In this report, when we use the term **Black**, we are referring to women and birthing people who identify as having African or Caribbean heritage or from any other Black or Caribbean background, including Somali.

We use the term **Brown** to refer to people who identify as having heritage from South Asia, East and South-East Asia (ESEA people) or any other Asian background, people from Latin-America and from other diasporic populations from around the world who do not identify as white.

We use the term **Mixed** to refer to people who have a mixed ethnic identity or identify as having more than one ethnic heritage or background (at least one of which is Black or Brown as defined above).

As far as possible, we are specific about the ethnicity of people in particular examples or case studies to illustrate the different experiences between ethnic groups. We also use the term ethnic minority/minorities in the report to describe broader groups of people.

<sup>&</sup>lt;sup>2</sup> Joint Committee on Human Rights, 2020, Black people, racism and human rights

### 2. Context

## Systemic racism and dehumanisation in maternity care

When analysing the evidence, we have drawn on the definition of institutional racism within the Macpherson inquiry into the death of Stephen Lawrence:

"The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping, which disadvantage minority ethnic people."

We broaden this idea to refer to "systemic racism" in this report, because the evidence we have gathered shows that racism goes beyond single institutions and infects national systems, policies and attitudes.

In understanding systemic racism in healthcare, it is critical to appreciate the long history of dehumanisation of Black and Brown people in the UK. Throughout modern history, Black and Brown people have been perceived by white societies as being sub-human and Black women specifically were subject to particular forms of abuse in healthcare settings, such as medical experimentation without consent and forced sterilisation. The medical model that exists in maternity care today was built on this patriarchal, white-supremacist framework.

The echoes of this structure continue to exist in the treatment of Black and Brown people outside the parameters of 'normal', as normal is based on whiteness as the standard. This has an ongoing impact on many aspects of Black and Brown peoples' lives, including access to and provision of healthcare. The evidence in our inquiry illustrates that systemic racism and dehumanisation exists in maternity care in ways which threaten basic human rights to safety, dignity, autonomy and equality.

 $<sup>^{\</sup>rm 3}$  Home Office, 1999, The Stephen Lawrence Inquiry: Report of an inquiry by Sir William Macpherson

<sup>&</sup>lt;sup>4</sup> Nuriddin, A. et al, 2020, Reckoning with histories of medical racism and violence in the USA

 $<sup>^{\</sup>rm 5}$  Roberts, D., 1997, Killing The Black Body: Race, Reproduction and the meaning of Liberty

We break systemic racism down into the following four categories, which highlight both the structural and interpersonal ways they manifest, and map onto the inquiry's calls to action.

Nature of racism	Examples	Calls to action
Individual interactions	<ul> <li>Being ignored and disbelieved</li> <li>Racist stereotypes and microaggressions</li> <li>Dehumanisation</li> <li>Denial of pain relief</li> </ul>	Commit to be an anti-racist organisation  Make Black and Brown women and birthing people decision-makers in their care and in the wider maternity system
Education and training	<ul> <li>White bodies as the 'norm' or default</li> <li>Failure to recognise conditions e.g. jaundice, sepsis</li> <li>Lack of cultural understanding</li> </ul>	Commit to be an anti-racist organisation  Decolonise maternity curriculums and guidance
Policies and frameworks	<ul> <li>Ethnicity as grounds for induction within policies</li> <li>'High risk' pathways based on ethnicity alone</li> <li>Lack of representation in clinical evidence and committees</li> <li>NHS charging regime and failure to provide interpreting</li> </ul>	Decolonise maternity curriculums and guidance  Make Black and Brown women and birthing people decision-makers in their care and in the wider maternity system  Dismantle structural barriers
Workforce	Lack of senior representation     Higher rates of disciplinary action	to racial equity through national policy change  Commit to be an anti-racist organisation
	Bullying and toxic culture	Create safe, inclusive workforce cultures

#### 2. Context Human rights in maternity care

Basic human rights to dignity, autonomy and equality are fundamental to achieving safe, respectful and inclusive maternity care. The Human Rights Act 1998 (HRA) applies to all public bodies in the UK, including NHS Trusts, NHS England and the Department of Health.

Human rights principles are also incorporated into the professional codes for healthcare professionals, the Care Quality Commission's inspection framework and policies of NHS bodies. These explain the role that healthcare professionals play in providing care in partnership with the woman to create an individualised plan of care for pregnancy, birth, and the postnatal period. This accords with human rights law, which requires that people are treated with dignity and respect.

The landmark legal case Montgomery v Lanarkshire Health Board<sup>7</sup> made clear that the person giving birth is the primary decision-maker in their care. This relies on establishing a relationship and dialogue with their care providers, where the midwife or doctor provides evidence-based information so that the woman or birthing person has the right information to make decisions about their maternity care. It is therefore essential that caregivers establish a respectful relationship with women and birthing people, listen to them and respond promptly and compassionately to concerns.

<sup>&</sup>lt;sup>6</sup> Nursing and Midwifery Council, 2019, Standards of Proficiency for Midwives and General Medical Council, 2019 Good Medical Practice

<sup>&</sup>lt;sup>7</sup> The Supreme Court, 2019, Montgomery vs Lanarkshire Health Board – press summary



#### Article 2 protects the right to life.

Providing safe maternity care is one of the ways that the state guarantees respect for this right. If a person dies during pregnancy or childbirth, the state may have violated Article 2 if systemic issues, rather than negligence by an individual clinician, contributed to their death.



#### Article 3 prohibits inhuman and degrading treatment.

The courts have defined this as treatment which causes intense physical or mental suffering (inhuman) or is extremely humiliating and undignified (degrading). In healthcare, Article 3 can be infringed by deliberate infliction of ill-treatment, negligence, or inadequate standards of care. Performing procedures without a person's consent, physical abuse, racist abuse or behaviour, failure to provide pain relief, or neglect in hospital wards, could all violate Article 3 if they caused intense suffering or humiliation.



### Article 8 protects the right to private and family life.

This includes "physical and psychological integrity", so hospitals must respect people's autonomy and decisions about maternity care. The European Court of Human Rights has said that Article 8 covers "the circumstances of giving birth", including choices about where, how and with whom to give birth. Informed consent is a core aspect of Article 8 and lack of informed consent to any aspect of maternity care will violate this right. Article 8 is a limited right and interferences with it can be justified if they pursue a legitimate aim and they are necessary and proportionate.



### Article 9 protects the right to freedom of thought, conscience and religion.

This protects a person's religious beliefs, customs and choices, including religiously-motivated choices about healthcare.

Like Article 8, the right to religion is a limited right and interferences with it can be justified if they pursue a legitimate aim and they are necessary and proportionate.



#### **Article 14** prohibits discrimination.

This entitles people to equal treatment in their enjoyment of all other rights and means it is unlawful for public bodies to discriminate against people on grounds including race, colour, language, religion, and national or social background.

### 2. Context **Existing evidence**

This inquiry builds on substantial evidence of persistent racial inequities in birth outcomes and experiences in the UK. The expert panel reviewed this literature at the outset, including US data where UK studies were not available. The wealth of existing statistical research informed our use of qualitative methodology, to gather the stories behind the statistics and address gaps in the evidence, such as the impact of racism and intersectional discrimination on mortality and morbidity.

#### Higher death rates

Evidence consistently shows higher death rates for Black, Brown and Mixed ethnicity women, compared to white women. Overall, deaths in pregnancy and childbirth remain relatively low in the UK (fewer than 1 in 10,000 pregnancies), but there are persistent, significant racial inequalities in maternal mortality rates.

The most recent MBRRACE report published in 2021 "shows a continued gap between the mortality rates for women from Black, Asian, mixed and white ethnic groups, with women from Black ethnic groups four times more likely to die than women from White groups". Asian and Mixed ethnicity women are almost twice as likely to die in pregnancy compared to white women. Apart from a slight drop in the maternal mortality rate for Black women, which MBRRACE found was not statistically significant, this bleak picture has not changed in over a decade.

MBRRACE previously reported further inequalities within these broad ethnic categories, with women born outside the UK significantly more likely to die than those born in the UK. Women born in Nigeria had the highest maternal mortality rate (34.2 per 100,000).

In the latest report, heart disease remains the leading cause of death, followed by epilepsy and stroke. Sepsis and blood clots are the third and fourth most common causes during or up to six weeks after the end of pregnancy.<sup>10</sup>

The 2020 MBRRACE report powerfully outlined how the women who died faced a "constellation of biases", which prevented them from receiving the care they needed. Multiple overlapping factors – being from an ethnic minority group, socioeconomic deprivation, social services involvement, language difficulties, mental ill health, obesity, domestic abuse – combine to increase the impact of the structural and cultural biases women experience in pregnancy.

<sup>&</sup>lt;sup>8</sup> MBRRACE-UK, 2021, Saving Lives, Improving Mothers' Care – Lay Summary

<sup>9</sup> MBRRACE-UK, 2014, Saving Lives, Improving Mothers' Care

<sup>&</sup>lt;sup>10</sup> MBRRACE-UK, 2021, Saving Lives, Improving Mothers' Care – Lay Summary

<sup>&</sup>lt;sup>11</sup> MBRRACE-UK, 2020, Saving Lives, Improving Mothers' Care – Lay Summary

### 2. Context **Existing evidence**

#### Higher rates of baby loss

Similar racial inequalities exist when looking at infant birth outcomes. In 2021, MBRRACE reported that "mortality rates remain exceptionally high for babies of Black and Black British ethnicity", with stillbirth rates over twice those for white babies and neonatal mortality rates 43% higher. For babies of Asian and Asian British ethnicity, stillbirth and neonatal mortality rates are both around 60% higher than for white babies.<sup>12</sup>

In 2020, MBRRACE concluded that while stillbirth rates have reduced by over 16% and neonatal mortality has reduced by 11% between 2013 and 2018, "rates of death are falling more slowly among [Black and Asian] babies compared to White babies" and thus initiatives to reduce baby loss are "failing to reach many women from higher risk ethnicities". 13

Other studies have found further inequalities within these broad ethnic groups. In 2017, the infant mortality rate was "highest among babies with a Pakistani ethnicity, at 7.3 deaths per 1,000 live births". Worryingly for UK maternity care, a 2020 study found Pakistani infants of Pakistan-born mothers have lower risks of neonatal death, infant death and preterm birth than Pakistani infants of UK-born Pakistani mothers. 15

A 2009 University of Oxford paper outlined how Caribbean and Pakistani babies were more than twice as likely as White British babies to die before the age of one and noted multiple complex factors, including the impact of systemic racism on both inter-generational health outcomes and maternity care experiences. It stated: "Empirical work on the impact of racism and racial discrimination on infant mortality among minority groups in England and Wales is lacking, however a number of US studies have reported a positive association between perceived racism and both preterm delivery and low birthweight".16

#### Higher illness rates

Black and Asian women are at higher risk of illness during pregnancy, which the pandemic has exposed and exacerbated. In 2020, NHS England reported that Black pregnant women were eight times more likely and Asian women four times more likely to be admitted to hospital with Covid-19, compared to white women. The Public Health England outlined how a combination of structural racism, socioeconomic disadvantage, housing challenges and occupation (frontline care, retail, transport) make Black and Asian people more likely to contract, become seriously unwell and die from Covid-19.18

The Royal College of Midwives notes "socio-economic disadvantage and being from a BAME background are closely associated with higher prevalence of obesity, diabetes, hypertension, and cardio metabolic complications", which increase the risk of both severe Covid-19 symptoms and pregnancy-related risks. <sup>19</sup> Yet an MBRRACE review of eight deaths from Covid-19 (seven from Black and minority ethnic groups) found that "pre-existing diabetes, hypertension or cardiac disease were identified in very few of these women". <sup>20</sup>

Pre-pandemic, other UK studies have concluded that despite the correlation between disadvantage and race, poverty does not explain maternal health inequalities between ethnic groups.<sup>2122</sup> A 2009 paper found that after adjusting for age and socioeconomic status, Black African and Black Caribbean women still had twice the incidence of severe maternal illness compared to white women.<sup>23</sup> Given the known correlation between some conditions and specific ethnic communities - such as sickle cell anaemia in people with an African or Caribbean background,24 thalassaemia in people of Mediterranean, south Asian, southeast Asian and Middle Eastern origin<sup>25</sup> and pre-eclampsia in Black women<sup>26</sup> the reduced access to or delays in care outlined in other studies (below) are all the more concerning.

Research also shows that rates of postnatal depression and anxiety are higher in Black, Asian and Mixed ethnicity women.<sup>27</sup> This is particularly concerning given that rates of access to perinatal mental health services are significantly lower in women and birthing people from these groups.<sup>28</sup>

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<sup>&</sup>lt;sup>12</sup> MBRRACE-UK, 2021, Perinatal Mortality Surveillance Report for 2019

<sup>&</sup>lt;sup>13</sup> MBRRACE-UK, 2020, Perinatal Mortality Surveillance Report for 2018

<sup>&</sup>lt;sup>14</sup> ONS, 2018, Child and Infant Mortality in England and Wales

Opondo, C. et al, 2020: Variations in neonatal mortality, infant mortality, preterm birth and birth weight in England and Wales according to ethnicity and maternal country or region of birth: an analysis of linked national data from 2006 to 2012

<sup>&</sup>lt;sup>16</sup> Gray R. et al, 2009, Inequalities in infant mortality project briefing paper 3. Towards an understanding of variations in infant mortality rates between different ethnic groups

<sup>&</sup>lt;sup>17</sup> NHS England, 2020, NHS boosts support for Black and ethnic minority women

<sup>18</sup> Public Health England, 2020, Beyond the data: Understanding the impact of COVID-19 on BAME groups

<sup>&</sup>lt;sup>19</sup> Royal College of Midwives, 2020, Covid-19 impact on Black, Asian and minority ethnic women

 $<sup>^{20}\,</sup>$  MBRRACE-UK, 2020, Learning from SARS-CoV-2-related and associated maternal deaths in the UK

<sup>&</sup>lt;sup>21</sup> Hollowell J, et al, 2011 Social and ethnic inequalities in infant mortality: a perspective from the United Kingdom

<sup>&</sup>lt;sup>22</sup> Davey Smith G. et al, 2000, Ethnic inequalities in health: a review of UK epidemiological evidence

<sup>&</sup>lt;sup>23</sup> Knight M., et al, 2009, Inequalities in maternal health: national cohort study of ethnic variation in severe maternal morbidities

<sup>&</sup>lt;sup>24</sup> NHS website: https://www.nhs.uk/conditions/sickle-cell-disease

<sup>&</sup>lt;sup>25</sup> NHS website: https://www.nhs.uk/conditions/thalassaemia

<sup>&</sup>lt;sup>26</sup> Chappell, L. et al, 2008, Demographic, Pregnancy, and Management Characteristics of 822 Women with Preeclampsia. This study found 79% of Black women developed pre-eclampsia vs 14% of white women.

Watson, H. et al, 2019, A systematic review of ethnic minority women's experiences of perinatal mental health conditions and services in Europe

<sup>&</sup>lt;sup>28</sup> Jankovic, J. et al, 2020, Differences in access and utilisation of mental health services in the perinatal period for women from ethnic minorities – a population-based study

### 2. Context **Existing evidence**

#### Worse experiences of care

UK studies report women in all minority ethnic groups had a poorer experience of maternity services than white women<sup>29</sup> and expressed more worries about labour and birth, especially in relation to pain, uncertainty about labour duration, and possible medical interventions.<sup>30</sup>

A 2010 survey of 24,300 women found significant differences in care that relate directly to basic human rights. Analysis found Black and Brown women faced more barriers to access and choice, and were less likely to be treated with dignity and respect, compared to white women. They were significantly less likely to report being sufficiently involved in decisions, to give birth at home or in a birth centre or to receive pain relief in labour, and were more likely to deliver by emergency caesarean.

MBRRACE has also found reduced access to or delayed care played a role in maternal deaths. In the 2014 report, while nine of the ten women from Nigeria who died received antenatal care, only one had the NICE recommended level of care (booking at less than 10 weeks and no antenatal appointments missed).<sup>32</sup> In the 2020 Covid-19 report, maternity care was extremely variable and many women had minimal or delayed obstetric or midwifery input, either to support planning birth or postnatally.<sup>33</sup>

#### Racism and stereotyping

US studies detail how racism directly impacts on healthcare. Stereotyping negatively influences diagnosis and treatment options made by clinicians, including pain management,34 reduces the level of healthcare people receive, either through direct care or from communication gaps in which crucial medical history details are missed or not shared,35 and leads to Black women "not [being] monitored as carefully as white women are. When they do present with symptoms, they are often dismissed".36 This creates a cycle where Black and Brown people avoid interactions with healthcare professionals through fear of potential prejudice and discrimination,<sup>37</sup> and, if they sense they are being stereotyped by professionals, are less likely to share information or to follow treatment advice.38



<sup>&</sup>lt;sup>29</sup> Henderson et al., 2013, Experiencing maternity care: the care received and perceptions of women from different ethnic groups

<sup>&</sup>lt;sup>30</sup> Redshaw and Heikkilä, 2011, Ethnic differences in women's worries about labour and birth

<sup>31</sup> Henderson et al., 2013, as above

 $<sup>^{\</sup>rm 32}$  MBRRACE-UK, 2014, Saving Lives, Improving Mothers' Care

<sup>33</sup> MBRRACE-UK, 2020, Learning from SARS-CoV-2-related and associated maternal deaths in the UK

<sup>&</sup>lt;sup>34</sup> K Hoffman et al., 2016, Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

<sup>35</sup> National Academy of Sciences (US), 2002, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, cited in https://www.heart.org/en/news/2019/02/20/why-are-black-women-at-such-high-risk-of-dying-from-pregnancy-complications

<sup>&</sup>lt;sup>36</sup> Harvard T.H. Chan School of Public Health, 2019, Why black women face a high risk of pregnancy complications

<sup>&</sup>lt;sup>37</sup> J. Dovidio et al., 2016, Racial biases in medicine and healthcare disparities

 $<sup>^{38}\,</sup>$  J. Aronson et al., 2013, Unhealthy Interactions: The Role of Stereotype Threat in Health Disparities

### 2. Context **Existing evidence**

#### Racism and stereotyping (continued)

US literature also highlights the historical roots of gynaecology in the experimentation and forced procedures on enslaved Black women, often without any pain relief.<sup>39</sup> A 2016 US report underlined how racist views about Black people and pain still persist, finding that half of a sample of white medical students held false beliefs about biological differences in Black and white physiology and pain perception, which create bias in treatment and care.<sup>40</sup>

While there is far less UK research on racism within healthcare, the Royal College of Obstetricians and Gynaecologists similarly noted in 2020 that "racial bias [...] can hinder consultations, negatively influence treatment options and can ultimately result in Black, Asian and minority ethnic women avoiding interactions with health services."41 In 2022, the Race and Health Observatory identified a major theme is "women's experiences of negative interactions, stereotyping, disrespect, discrimination and cultural insensitivity. System-level factors, as well as the attitudes, knowledge and behaviours of healthcare staff, contribute to some ethnic minority women feeling 'othered', unwelcome, and poorly cared-for".42

The 2020 Turning the Tide report went further in describing examples of racism and stereotyping within NHS maternity care. Healthcare professionals described a common midwifery and obstetric perspective that "Asian women have a shorter perineum" but without defining "shorter than whom", based on medical literature that assumes anatomy is compared to a 'white norm'. There were also incidents reported of "non-BAME maternity staff having acted on the mistaken belief that 'Black women have a higher pain threshold than other women' which has had a negative impact on the experience of Black patients".43

Other UK studies have found that midwives stereotypically view Asian women as needing less support, being generally well supported by their families, having a lower pain threshold in labour and a tendency to "make a fuss about nothing", and being too demanding.<sup>44</sup>

#### Intersectional discrimination

Birthrights has previously found that age, disability, ethnicity, language and migrant status compounded human rights issues in pregnancy and childbirth, especially in relation to stereotypes, choice and consent. 45 Maternity Action documents how NHS charging rules deter undocumented migrant women from accessing maternity care due to fear of the costs and of referral to the Home Office.46 In the US, perceptions of race and mental capacity intersect to disproportionately undermine or override Black and Brown women's autonomy<sup>47</sup> - such as in the case of Rinat Dray, forced to have a caesarean against her will, whose legal advocates contend that racism was a factor in her treatment.48

Other studies outline how racial and religious discrimination intersect: for Muslim women, poor care is found to be linked to "stereotypical and discriminatory behaviour", lack of awareness or understanding of Islam, and their clothing (veil or hijab) making them more prone to discrimination.<sup>49</sup> Muslim Somali women have reported that when accessing healthcare, including during pregnancy, they are repeatedly asked if they have experienced female genital mutilation (FGM), which can be insensitive, intrusive and re-traumatising.<sup>50</sup>

There is limited research on ethnicity, sexuality and gender identity in the context of pregnancy and childbirth. MBRRACE statistics do not specify whether these deaths include trans men and non-binary people, or cis women only. Yet trans people experience some of the greatest health disparities<sup>51</sup> and unequal treatment while accessing healthcare in general.<sup>52</sup> A 2022 LGBT Foundation report found that "transphobia and racism in perinatal care intersect to produce particularly poor outcomes for trans and non-binary birthing parents of colour", often experienced as a lack of action, empathy or appropriate care.53

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 $<sup>^{39}</sup>$  Ojanuga, D., 1993, The medical ethics of the 'Father of Gynaecology', Dr J Marion Sims

<sup>&</sup>lt;sup>40</sup> Hoffman, K., et al, 2016, Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

<sup>&</sup>lt;sup>41</sup> Royal College of Obstetricians and Gynaecologists, 2020, Position Statement: Racial disparities in women's healthcare

<sup>&</sup>lt;sup>42</sup> Race and Health Observatory, 2022, Ethnic Inequalities in Healthcare: A Rapid Evidence Review

<sup>43</sup> NHS, 2020, Turning the Tide: The experiences of Black, Asian and Minority Ethnic NHS staff working in maternity services in England during and beyond the Covid-19 pandemic

<sup>&</sup>lt;sup>44</sup> Jomeen J, Redshaw M, 2012, Ethnic minority women's experience of maternity services in England and Bowler I, 1993 'They're not the same as us': midwives' stereotypes of South Asian descent maternity patients

<sup>&</sup>lt;sup>45</sup> Birthrights and Birth Companions, 2019, Holding it all together and Birthrights, Bournemouth University and University of Liverpool, 2018 The Human Rights and Dignity Experience of Disabled Women during Pregnancy, Childbirth and Early Parenting

<sup>&</sup>lt;sup>46</sup> Maternity Action, 2019, Duty of care? The impact on midwives of NHS charging for maternity care

 $<sup>^{47}</sup>$  Scott, R., 2002: Rights, Duties and the Body: Law and ethics of the maternal-fetal conflict

<sup>&</sup>lt;sup>48</sup> National Advocates for Pregnant Women, 2020, Amicus Briefs Filed in Support of Rinat Dray in Her Ongoing Fight For Justice

<sup>&</sup>lt;sup>49</sup> Firdous et al, 2020, Muslim women's experiences of maternity services in the UK

<sup>50</sup> Karlsen, S. et al, 2020, 'Putting salt on the wound': a qualitative study of the impact of FGM-safeguarding in healthcare settings on people with a British Somali heritage living in Bristol, UK

<sup>&</sup>lt;sup>51</sup> Women and Equalities Select Committee, 2019, Health and Social Care and LGBT Communities

<sup>52</sup> Stonewall, 2018, LGBT in Britain: Trans Report

<sup>&</sup>lt;sup>53</sup> LGBT Foundation, 2022, Trans and Non-Binary Experiences of Maternity Services

### 2. Context Policy context

Numerous national initiatives have sought to address racial inequalities in maternity care, with little impact to date on the disproportionate death rates. Birthrights is concerned that most of these initiatives overlook the role of systemic racism or perpetuate the view that Black and Brown bodies are the problem and clinical interventions offer the only cure.

#### Targeted continuity of carer

In 2019, the NHS Long Term Plan set out a goal that "by 2024, three-quarters of pregnant women from Black, Asian and minority ethnic communities will receive care from the same midwife before, during and after they give birth".<sup>54</sup> With two years to go, NHS Trusts have now been told that they must be able to demonstrate safe staffing levels before proceeding with their planned rollout.<sup>55</sup>

Nevertheless, the national commitment to deliver continuity of care for 75% of women from Black, Asian and minority ethnic communities and from the most deprived groups is restated in the 2021 NHS Core20PLUS5 approach to reduce health inequalities, which includes maternity as one of five clinical areas of focus "requiring accelerated improvement".56

Birthrights supports the safe and targeted rollout of continuity of carer, given the evidence of positive outcomes for women and babies in general, and specifically in socially disadvantaged and Black, Asian and minority ethnic groups,<sup>57</sup> but it must be accompanied by robust anti-racism and cultural safety training – and is not sufficient alone to address systemic racism within maternity care.

24

#### Equity and equality guidance

In 2020, NHS England and Improvement also published its Equity and Equality Guidance for local maternity systems, which includes explicit pledges "to improve equity for mothers and babies and race equality for staff."58 This twin focus, the emphasis on cultural competency training and recognition of how racial discrimination in the workforce in turn impacts on outcomes for women and birthing people are all welcome. However, NHS England does not have a target to end the disparity in maternal death rates for Black women and the Joint Human Rights Committee has criticised the NHS for this failure.59

Birthrights and the inquiry expert panel noted that the NHS England guidance overlooks the role of systemic racism, class bias and other oppressions in maternity care experiences and outcomes, which means it cannot fully identify the right solutions. Most of the recommended interventions are not new and focus on pre-conception health or pre-existing conditions only e.g. smoking, diabetes, genetics. As one expert panel member commented: "vitamins do not cure racism". The panel also queried whether the funding allocated to local maternity systems is sufficient given the scale and pace of ambition, and the ongoing acute pressures within maternity services.

#### **Government initiatives**

The Ministerial Maternity Disparities Taskforce announced in February 2022 also sets out to tackle disparities in maternity care experienced by women from ethnic minority groups and those living in deprived areas. 60 Birthrights welcomes the focus on personalised care and informed decision-making, which are core to rights-respecting care. However, while pre-conception health is an important factor, focussing primarily on supplements and weight falls into the trap of blaming Black and Brown bodies for worse outcomes. To date, there is also no explicit reference to the important concept of 'weathering' - the lifetime impact of everyday racial trauma and discrimination on health, including on pre-existing conditions.61

Similarly, while the Office for Health Improvement and Disparities has a remit covering maternal health, this focuses on a lifetime approach, preventable risk factors and pre-conception health. These are all crucial factors, but again, it overlooks the impact of racial discrimination and trauma on health through lifetime 'weathering', past experiences leading to a breakdown of trust and affecting interactions with services, and direct discrimination and systemic racism within maternity care.

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<sup>&</sup>lt;sup>54</sup> NHS England and Improvement, 2019, The NHS Long Term Plan

<sup>55</sup> NHS England and Improvement, 2022, Ockenden final report letter to NHS Trusts

<sup>56</sup> NHS England and Improvement, 2021 https://www.england.nhs.uk/about/equality/equality-hub/core20plus5

<sup>&</sup>lt;sup>57</sup> Homer, C. et al, 2017, Midwifery continuity of carer in an area of high socio-economic disadvantage in London: A retrospective analysis of Albany Midwifery Practice outcomes using routine data (1997–2009)

 $<sup>^{58}\,</sup>$  NHS England and Improvement, 2021, Equity and Equality Guidance for local maternity systems

<sup>&</sup>lt;sup>59</sup> Joint Committee on Human Rights, 2020, Black people, racism and human rights

<sup>&</sup>lt;sup>60</sup> Department for Health and Social Care, 2022, New taskforce to level-up maternity care and tackle disparities

<sup>&</sup>lt;sup>61</sup> Geronimus, A T, 1992, The weathering hypothesis and the health of African-American women and infants: evidence and speculations

### 2. Context Policy context

#### Tackling racism and discrimination

In contrast, the independent NHS Race and Health Observatory that was established in 2020 has identified maternity and neonatal care as areas requiring urgent attention, and explicitly recognised the need to address systemic racism and discrimination. Birthrights welcomes their recommendation that

"There needs to be a serious commitment from NHS England and NHS Improvement to tackle racist attitudes and behaviours among healthcare staff, and address structural dimensions of NHS systems that discriminate against ethnic minority women and their babies".62

Our inquiry calls to action support these aims.

We also welcome the Royal College of Midwives' call for improvements in midwifery education so that student midwives are taught how to better assess women and babies with darker skin tones, as part of a motion to 'decolonise the midwifery curriculum' to the TUC Black Workers' Conference in May 2022.63

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 $<sup>^{62}\,</sup>$  NHS Race and Health Observatory, 2022, Ethnic Inequalities in Healthcare: A Rapid Evidence Review

<sup>&</sup>lt;sup>63</sup> Royal College of Midwives, 2022, Improve midwifery education about skin colour to make maternity care safer says RCM

### 2. Context State of maternity care

It is impossible to examine the issue of racial injustice within maternity services without appreciating the wider structural issues affecting maternity and health services within the UK. A history of chronic underfunding and staff shortages have impacted on the quality and safety of care being delivered.

The Ockenden report cited midwife shortages and a toxic culture of staff being silenced as two of the major factors in failings at Shrewsbury and Telford NHS Trust which led to preventable deaths of women and babies.<sup>64</sup> Latest figures report that England is over 2,000 midwives short of the number needed to serve the population, and this is set to get worse as 330 FTE staff left the profession in the year to November 2021.<sup>65</sup>

Staff shortages within maternity care have been an issue for many years and the impact of Brexit and the Covid-19 pandemic have only made the situation worse. The Turning the Tide report, which focussed on the experiences of Black, Brown and Mixed ethnicity maternity staff working throughout the pandemic, highlighted how they felt scared, anxious and worried about their physical and mental health, reporting that they did not feel safe or supported at work, including when seeking support for managing their own health; faced a lack of personal protective equipment (PPE) and acknowledgement of the psychological impact; and did not feel they were able to raise concerns for fear of retribution.66

The breakdown in UK maternity staffing has a profound impact on the basic human rights of everyone who uses maternity services, but systemic dysfunction is likely to have a disproportionate impact on marginalised groups who already face barriers to accessing care.

Inquiry process

<sup>&</sup>lt;sup>64</sup> Department of Health and Social Care, 2022, Final report of the Ockenden review

 $<sup>^{65}</sup>$  Royal College of Midwives, 2022, Maternity staffing shortage hitting quality and safety RCM tells politicians

<sup>66</sup> NHS East London, 2020, Turning the Tide: The experiences of Black, Asian and Minority Ethnic NHS staff working in maternity services in England during and beyond the Covid-19 pandemic

### 3. Inquiry process The expert panel

Birthrights convened an expert panel to lead the inquiry. The panel met six times from February 2021 to January 2022: to agree the scope, terms of reference and methodology; to review emerging findings and advise on the participation approach; to hear oral evidence at three sessions; and to agree themes from the evidence and co-create the calls to action.



Co-chair (expert by experience)
Sandra Igwe

Founder of The Motherhood Group and Black Maternal Mental Health Awareness Week, and Birthrights Trustee



Caroline Bazambanza

PhD Candidate in the Department of Anthropology at the London School of Economics exploring the Black maternal experience at the intersections of reproduction, race and welfare



**Tracey Bignall** 

Senior Policy and Practice Officer at the Race Equality Foundation and member of NHS England's Maternity Transformation Stakeholder Council



Inquiry Chair

Shaheen Rahman QC

A senior barrister with particular expertise in Clinical Negligence, Inquests, Public Law and Human Rights



Co-chair (maternity professional)
Benash Nazmeen

Assistant professor of midwifery with a specialist interest in equity, diversity and inclusion; Trustee of Iolanthe Midwifery Trust; and founder of the Association of South Asian Midwives



Benjamin Black

Consultant obstetrician and gynaecologist in London and specialist adviser in maternal, sexual and reproductive health in humanitarian and complex emergencies



Dr Ria Clarke

Practising obstetrician, with a public profile speaking out on motherhood, working in the NHS, intersectional feminism and anti-racism



Elsie Gayle

Midwife in private practice with significant national and international experience, advocate of culturally safe care and on inequalities, especially faced by women of African descent



Meera Khanna

Expert by experience who then founded the Nest Club to improve postnatal care



**Mars Lord** 

Triple award-winning doula, mentor, educator and coach, Black birth activist, founder of Abuela Doulas, Vice-Chair of Iolanthe Midwifery Trust and Birthrights Trustee



#### Natasha Smith

Expert by experience, doula and holistic therapist, Trustee at White Ribbon Alliance UK, Founder and Managing Director of the Women's Health and Maternal Well-being Initiative C.I.C.



Sabrina Stewart

Expert by experience who now advocates for others, Maternity Voices Partnership user rep in Jersey



Jenine Gill

Equalities and human rights lawyer with professional experience of inquiries and recent lived experience, taking part in a personal capacity



**Olive Lewin** 

Clinical negligence lawyer at Leigh Day who specialises in birth injury claims



#### **Lorraine Pryce**

Expert by experience and doula working with clients facing discrimination and disadvantage, e.g. people of colour, non-binary people, solo parents, people who have had a difficult fertility journey



**Georgie Watson** 

Birth supporter, founding Chair of Kernow Maternity Voices Partnership within Cornwall and the Isles of Scilly, with experience of working with and advocating for vulnerable and marginalised families

# 3. Inquiry process Who did the inquiry reach?

As a primary goal was to understand the stories behind the statistics, we adopted a qualitative methodology for evidence-gathering, rooted in a trauma-informed approach. The terms of reference, detailed methodology and limitations are set out in the appendix.

The panel held three oral evidence sessions with experts and decision-makers. Nova Reid, the acclaimed writer, speaker and anti-racism expert, acted as an adviser to the panel. Birthrights commissioned a poll by Survation with a sample of 1,069 respondents, to compare the experiences of Black, Asian and Mixed ethnicity women with white women.

Unless otherwise specified, anonymous quotes in the findings and evidence chapter are from respondents to the call for evidence or participants in focus groups and interviews.

The inquiry heard directly from **over 300 people** with lived and professional experience of racial injustice in maternity care:

244
responses to the written
call for evidence

focus groups – reaching 50 women and 5 midwives

14

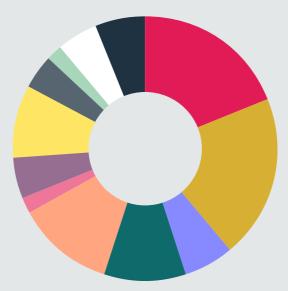
in-depth interviews – with 3LGBTQ+ birthing people/partners,2 women, 1 midwife and 8 clinical negligence solicitors/barristers

We commissioned a poll with Survation to compare the experiences of

1,069

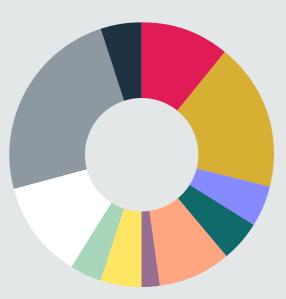
women who gave birth in the last 5 years – 556 white and 513 Black, Asian and Mixed ethnicity.

#### Birthrights call for evidence 187 women and birthing people



Black African	19%	36
Black Caribbean	20%	37
Other Black background	6%	1
Indian	10%	19
Pakistani	12%	22
Bangladeshi	2%	3
Chinese	0%	(
Other Asian background	5%	10
White and Black Caribbean	9%	17
White and Black African	4%	-
White and Asian	2%	2
Any other mixed background	5%	10
Arab	0%	(
Not disclosed	6%	1
Total	100%	187

### 57 healthcare professionals



Black African	11%	6
Black Caribbean	18%	10
Other Black background	5%	3
● Indian	5%	3
Pakistani	9%	5
Bangladeshi	0%	0
Chinese	0%	0
Other Asian background	2%	1
White and Black Caribbean	5%	3
White and Black African	0%	0
White and Asian	4%	2
Any other mixed background	12%	7
<ul><li>White</li></ul>	24%	14
● Not disclosed	5%	3
Total	100%	57

Focus group	S			
0000000	African Community (	Centre		
Swansea Women's		sylum seeker an	d Refugee Group	
000	Raham Project			
0000	Latin American Asso	ciation		
	Happy Baby Commu	ınity - Kurdish		
0000	Happy Baby Communication	ınity - Arabic		
	Happy Baby Communication	nunity – Yoruba/English		
000000	Happy Baby Commu	······ <del>-</del>	nity - Urdu	
0000	Happy Baby Commu			
	Leeds NHS Maternity		hip	
	Healthcare professio	onals		
Interviews				
000	LGBTQ+ birthing peo	ple and partners	;	
Women				
	Midwife			
•••••	Clinical negligence s	solicitors and bar	riers	
Survation po	oll	Language		
Ethnicity		Is English your first language?		
556 White		White	Black and Brown	
145 Black or Bl	lack British	Yes <b>90%</b>	Yes <b>73%</b>	
227 Asian or A	sian British	No 10%	No <b>2</b> 6%	
141 Mixed			Prefer not to say 19	
1,069 Total		Gender iden	itity	
		Is your gender identity the same as the sex you were assigned at birth?		
		White	Black and Brown	
		Yes <b>97%</b>	Yes <b>95%</b>	
		No 3%	No 5%	
		_	Prefer not to say 1	
Sexuality		White	Black and Brown	
Sexuality How would you	Straight/heterosexual		Black and Brown 88%	
How would you describe your	Straight/heterosexual Gay			
How would you		93%	88%	
How would you describe your	Gay	93% 1%	88% <mark>1</mark> %	
How would you describe your	Gay Bisexual	93% 1% 4%	88% 1% 8%	

The expert panel held three oral evidence sessions with decision-makers and experts in June, July and September 2021.

#### June 2021

Lived experience and intersectionality, with Maternity Action (migrant women and NHS charging) and Black Beetle Health (LGBTQ+ people of colour);

#### July 2021

Healthcare professionals'
experiences, with the Royal
College of Obstetricians and
Gynaecologists, Royal College
of Midwives, and Nursing and
Midwifery Council;

#### September 2021

Policy and systems change, with the National Institute for Health and Clinical Excellence and MBRRACE-UK.

These were closed sessions to foster safe, open and robust debate – they were not live-streamed and detailed transcripts were not published.

This chapter summarises the main evidence presented, questions raised and challenge posed by the panel – all of which informed this report's conclusions and calls to action.

Anonymous quotes in this chapter are from members of the expert panel.

We are grateful to everyone who contributed, including Nova Reid who advised the panel for the first two sessions and supported development of the inquiry calls to action, to ensure we applied an anti-racist framework to discussions and conclusions.

Session one:
lived experience
and intersectionality

The June session focussed on the prominent emerging themes and filling gaps in the evidence from marginalised groups experiencing intersectional discrimination – specifically Black and Brown migrant women and LGBTQ+ birthing people.

The panel heard recordings of six case studies drawn from the written evidence submitted to the inquiry's call for evidence. These represented a range of ethnicities and illustrated emerging themes such as racial microaggressions and stereotyping, failure to recognise serious medical conditions due to skin colour, lack of respect for culture and religion, breaches of consent, and trauma. In response, panel members shared relevant personal and professional experiences. Panel members highlighted how the case studies underlined that "the system was not built to support Black and Brown people, from the education to the imagery, to the understanding of race and culture".

Other points of discussion included: colourism – women and birthing people with darker skin facing the worst experiences and outcomes; blame culture in maternity care – fear of retribution for speaking out and examples of staff losing their jobs for raising concerns about racism; defensiveness and denial – some healthcare professionals who believe "I treat everyone the same" and do not see or recognise how racism impacts within maternity care and the harms it causes.

Maternity Action presented to the panel about NHS charging for maternity care, based on intelligence from their advice service, which supports c.400 people affected a year, and casework with asylum-seekers and refugees, undocumented destitute migrant women, victims of trafficking, and survivors of domestic or sexual violence. Their evidence and case studies highlighted how NHS Trusts often do not apply exemptions set out in government guidance in relation to violence or destitution.

Issues include lack of procedures and patients not being notified about exemptions, known information about violence not being shared with overseas visitor managers, and the option to write off debts not being offered as an option to undocumented destitute women - or being refused when challenged. In one case, despite disclosing severe domestic violence to her midwife, a woman was charged over £15,000 and was never told about the relevant exemption. A British citizen and dual national who became pregnant overseas but lived in the UK was identified as chargeable, despite meeting the 'ordinary residence test' and being exempt.

"Offering safe care is not just about what training we may have done or the work we do to address our own biases, we are only safe if the person we are supporting feels safe."

In response, the panel discussed racial profiling, which was raised in some of the written testimony to the inquiry and echoed in professionals' experiences such as in a maternity unit close to an airport, seeing "Black women subjected to scrutiny, white women (still overseas residents but from places like Australia), given much more grace". Other concerns related to regional and age variation in how charging is applied, lack of any analysis of charging by country or origin to explore any discrimination against certain nationalities or ethnicities, and the lack of accountability or regulatory review for Trusts failing to apply these national exemptions.

Finally, Black Beetle Health shared emerging findings from the interviews commissioned for the inquiry with LGBTQ+ people. Interviewees were Black British African, Black British Mixed Ethnicity and British Asian, there was one partner, and the cohort represented a range of sexualities and genders, including trans. A strong theme that echoed the inquiry's general findings was not being listened to – dismissal, lack of compassion and power dynamics in relation to a white partner being taken more seriously than the Black pregnant person.

People described being racialised by the nature and focus of questions asked by caregivers, a deep and persistent fear of death related to 'knowing and not knowing' the maternal mortality statistics, and healthcare professionals' lack of knowledge and time pressures impacting on personalised care. Interviewees referred to being "stealth" and not feeling comfortable to disclose their queer identity when accessing maternity care.

Surviving birth, having a healthy baby, midwives and continuity of carer were identified as positives.

Panel members were struck by the depth of fear expressed, with one reflecting that "offering safe care is not just about what training we may have done or the work we do to address our own biases, we are only safe if the person we are supporting feels safe." Others shared experiences of staff shortages and time pressures undermining safety, and even of being reprimanded for spending too long establishing relationships with the people in their care.

We discussed that a vital antidote to the level of fear expressed is celebrating Black and Brown birth, to help mitigate the concerns for individuals: "We can know the statistics, we can know the issues, we can do the work and still celebrate the amazingness of growing and nurturing our families. There is a lack of alternative narrative. We need ourselves reflected more in the 'good' things."

Session two: healthcare professionals' experiences

The July session focussed on testimony from healthcare professional bodies about their respective race equity work and their members' or registrants' perspectives on racial injustice in maternity care.

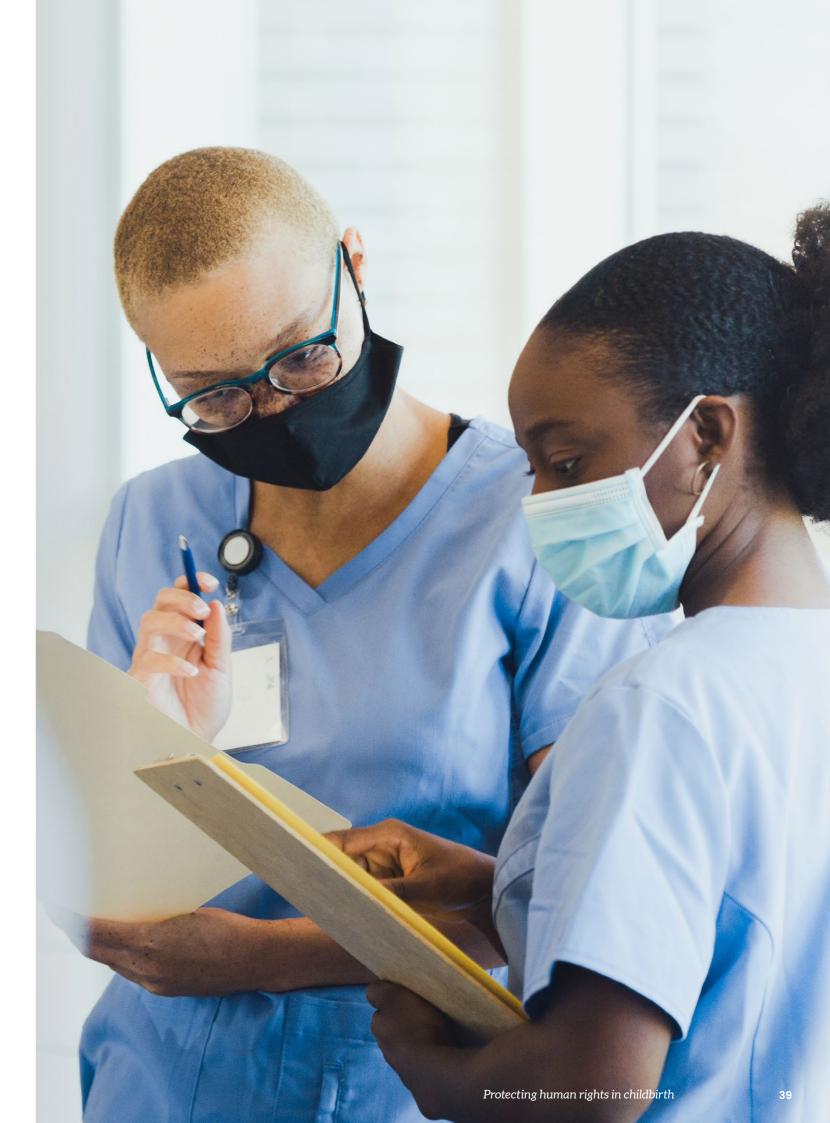
The panel also heard recorded excerpts from the focus group held with midwives for the inquiry, which underlined core themes across the evidence such as NHS culture of blame and fear, lack of senior representation and witnessing or experiencing overt racism – with no process or protection to escalate concerns.

The Royal College of Obstetricians and Gynaecologists (RCOG) presented the work of their Race Equality Taskforce,<sup>67</sup> established in 2020, outlining in detail the work underway across three workstreams: the work of the RCOG, training and careers, and women's health outcomes. Goals of stream one are to create a compulsory training and inclusivity agenda for all staff, officers and executives; strengthen public and patient engagement across the RCOG; influence national audits to apply an inclusive framework from design to evaluation; develop new focus areas for research and seek funding: review RCOG products including Green Top Guidelines, patient information and good practice papers.

Stream two focuses on understanding and addressing racism and differential attainment in trainees, members and fellows, through raising awareness, representation and positive inclusion, training and education. Data presented showed the scale of the challenge: Black and minority ethnic O&G doctors had a significantly lower pass rate compared to their white peers which is unchanged in a decade. Stream three takes a life course approach to understand the multi-level impacts of societal, health system and individual factors on racial inequalities in women's health outcomes. Long-term aims include identifying targets for the reduction in perinatal and neonatal mortality, supporting research into poor outcomes and experiences, and building links with GP and community services.

The expert panel welcomed the Taskforce's explicit focus on racism and extensive programme of work already underway, including with a broad range of partners. Points of discussion and challenge included: emphasising action not just research - the need for a rapid response to what we know now, e.g. disseminating urgent mandates on how jaundice and sepsis present in darker skin; how to rollout compulsory training when working with people who not do want to engage in anti-racism, and what consequences or accountability might be appropriate; how ensure a common approach to education across RCOG guidelines and the medical curriculum led by universities.

Panel members also raised their direct experiences of the lack of Black or Asian lay examiners and of examination scenarios including race or ethnicity.



<sup>&</sup>lt;sup>67</sup> RCOG Race Equality Taskforce: https://www.rcog.org.uk/about-us/campaigning-and-opinions/race-equality-taskforce

Prioritising inclusive recruitment of lay examiners and content on racism and microaggressions within both training and assessment is an essential aspect of decolonising the curriculum which still centres white bodies as the norm.

The Royal College of Midwives (RCM) gave evidence on their members' experiences and the Race Matters campaign. They shared intelligence from Black, Asian and other mixed ethnicity midwives and midwifery support workers which highlights that they are less likely to join, trust and become active in the RCM; more likely to be disciplined at work or referred to the Nursing and Midwifery Council and receive harsher outcomes; more likely to experience bullying, harassment and undermining behaviours at work from both clients and colleagues; less likely to be promoted and developed into senior roles.

Race Matters was developed with independent challenge, criticism and advice from equality charity Brap and sets out five pledges to RCM members: train all staff and activists to recognise and challenge racism; listen to and learn from members; challenge discrimination in the workplace; be more representative of the membership – from the Board through to every project group; champion better care for Black, Asian and ethnic minority women.

The expert panel welcomed the RCM's explicit acknowledgment of how far they still need to go to achieve these five pledges. Questions and discussion covered: ensuring anti-racism trainers are experts in this work, not just a group of passionate

Black and Brown members; the need to breakdown the increase in Board members 'of colour' to understand which ethnicities are included and what gaps remain; clarity about how Board members are recruited: "Does it show a clear desire to recruit minoritised and historically excluded people?"; how to ensure new recruits are respected, listened to and that RCM groups or Boards are culturally safe. Panel members recommended cultural safety as the core competency instead of cultural sensitivity - as it "moves beyond sensitivity to analysing power imbalances, which is the fundamental basis for racism" and emphasised the need for widespread communications about Race Matters so it reaches all members. They also sought reassurance about support for staff who report bullying, harassment and racism.

The Nursing and Midwifery Council (NMC) gave evidence focussed on their Future Midwife Standards of proficiency published in 2019, highlighting the focus on person-centred care, human rights, cultural and spiritual safety, and health and social inequalities.69 The NMC had mapped the Standards against the 2020 Turning the Tide report on experiences of Black, Asian and minority ethnic maternity staff and described how the Standards' "domains" (expectations of knowledge, skills and experience) align with this report's recommendations to support racial equity for staff and patients. They also outlined the NMC's 2020 Ambitious for Change research, which found differences in experiences and outcomes of NMC processes linked to ethnicity, gender and sexuality.

These included lower acceptance rates onto education courses for Black and Asian students; lower chances of registering through overseas processes for Black professionals; higher rates of referrals to Fitness to Practise for Black professionals. To address this, further external research, improvements to data, and changes to overseas registration, revalidation and fitness to practise are underway.

In response, the expert panel stressed the need to centre racism explicitly within the Future Midwife Standards, as broader references to discrimination or health inequalities are not sufficient. Referencing microaggressions and stereotypes within the Standards and other frameworks would also support improved racial fluency among the workforce. Other changes proposed by the panel were: introduce mandatory anti-racism training for all NMC staff and expert advisors; revise the NMC Code to state expected standards of behaviour in relation to providing culturally safe care and tackling racism; specify training on anti-racism and cultural safety as a mandatory part of the midwifery revalidation process.

Discussion focused on the need for diverse imagery and specific language (not "BAME") across internal and external resources, leadership targets broken down by different ethnicities and which reflect a range of grades and roles, and clarity about the action NMC are taking to reach out to and support Black and Brown midwives. The panel also raised concerns about high-profile examples of NMC members who were not sufficiently held to account for racist behaviour.

After the session, the NMC published the review into their handling of the Fitness to Practise case of Melanie Hayes, who admitted to making racially abusive comments about colleagues between 2012 and 2018 and a threatening comment about a patient. The original NMC panel agreed a six month suspension, but she was subsequently struck off by the High Court. The NMC's review found their original decision "didn't sufficiently weigh up the seriousness and nature of the racial abuse".70 This underlines the importance of NMC's commitment to an independent review of Fitness to Practice, which we believe must interrogate whether the process is structurally racist and discriminatory.

<sup>&</sup>lt;sup>68</sup> Royal College of Midwives, 2021, Race Matters - A statement by the RCM

<sup>&</sup>lt;sup>69</sup> Nursing and Midwifery Council, 2019, Standards of Proficiency for Midwives

Nursing and Midwifery Council, 2021, Looking back, learning lessons and improving: Discrimination in health and care: learning from a recent fitness to practise case

Session three:
policy and
systems change

The September session focused on clinical and research bodies, with witnesses from the National Institute for Health and Clinical Excellence (NICE) and MBRRACE-UK. We also invited NHS England and Improvement to give oral evidence, but they declined to attend. Instead, the expert panel reviewed NHS England's Equity and Equality guidance for local maternity systems, highlighting gaps and concerns as set out in the policy context section.

NICE gave an overview of its purpose to produce guidance for the health and social care system based on the 'best available evidence' and outlined how they apply the Public Sector Equality Duty across their work. Equality impact assessment is integrated into each step of the guidance production process: scoping, development, consultation and finalisation - and they shared some examples of how this has been applied in relation to race and ethnicity. They addressed the draft inducing labour guideline that had attracted substantial criticism for its blanket proposal to single out Black, Asian and minority ethnic women for induction at 39 weeks, acknowledging they got the draft wrong and committing to learning lessons about the process (this proposal was dropped in the final version of the proposal). NICE also invited feedback on areas including: representation in leadership, the workforce and advisory

groups; topic selection, process and methods; limitations in the availability and quality of 'best available evidence'.

Discussion mainly focussed on the inducing labour guideline, given the widespread concern that singling out particular groups for different treatment without evidence that it improves outcomes is racist and discriminatory. The expert panel expressed significant concerns about how such a blanket proposal could be recommended and then published by NICE, even in draft form, given it was not based on evidence but on professional opinion among the guideline group. Questions were asked about who decides what evidence is deemed 'valid', how representative NICE guideline and stakeholder groups are in terms of ethnicity and race, how maternity organisations can support NICE to prevent such a flawed decision from happening again, and how NICE will rebuild trust and embed much earlier engagement with stakeholders and people affected. Professionals flagged that even draft guidelines can quickly impact on care, with colleagues already repeating views about gestation being different based on ethnicity, despite the lack of robust evidence. "Once these 'recommendations' are out there we know that they stick and the belief remains even though it is not based on robust evidence. Look how long it has been believed that Black and Brown skinned people have higher pain thresholds and what that has done to our care."

The panel proposed that NICE review its processes for evaluation and recommendations – to be open about how evidence has been deemed valid and by whom, take a broader approach to the

"Once these 'recommendations' are out there we know that they stick and the belief remains even though it is not based on robust evidence."

types of evidence considered at an early stage, be clear where there is lack of evidence, and push for research to address gaps. They urged more transparency about ethnic representation in guideline groups and advisory committees, clear targets to recruit more diverse professional and lay experts, and equitable processes to support Black and Brown people to engage with groups and consultations. As for the professional bodies, anti-racism and cultural safety training for all NICE staff is essential.

MBRRACE-UK presented their (then unpublished) report looking at maternal deaths from 2009 to 2018, to compare the quality of care received by women from different aggregated ethnic groups and identify any structural or cultural biases or discrimination affecting their care.71 The analysis found no major differences in causes of death, with cardiovascular disease the leading cause of death in all ethnic groups. From reviewing maternity notes, the research identified multiple microaggressions experienced by women who died, echoing many themes in our inquiry evidence. Microaggressions MBRRACE identified included:

- women not being listened to despite repeat presentations;
- agitation in women who did not speak English was attributed to mental health problems when women were severely physically unwell;
- Black British women said to have a 'low pain threshold';
- being called 'difficult' when hypoxic (experiencing inadequate levels of oxygen)
- varying descriptions of women's ethnic group and origins throughout their

- records, from generic terms such as Afro-Caribbean to detailed country of birth – one woman was described variously as Caribbean, from Sierra Leone and from Jamaica;
- issues with quality of interpretation and continued reliance on interpretation by family members;
- assumptions around symptoms made on the basis of language ability and/or ethnic group.

MBRRACE found that microaggressions occurred in all ethnic groups but were most common in Asian women. Lack of individualised care - being treated inappropriately due to deliberate or unintentional lack of recognition of women's needs - was notable among Black women who died. Discussion with the expert panel focussed on research limitations, including: representation among the co-investigator group and how this may have impacted on identification of microaggressions; issues with the aggregated ethnic categories and numbers being too small to compare nuances between ethnic groups; working only with medical records and on care of women who died, meaning women's voices are missing. Given 'defensive writing' can be a feature of maternity and other healthcare notes, with women and families often raising concerns about missing or amended information, the panel raised what other microaggressions or racist views and behaviours are not being recorded. Notwithstanding the limitations acknowledged by MBRRACE, this new analysis is powerful and correlates with the findings on microaggressions in this inquiry's evidence.

<sup>&</sup>lt;sup>71</sup> Knight, M. et al, 2022, A national cohort study and confidential enquiry to investigate ethnic disparities in maternal mortality

### 3. Inquiry process Summary of poll findings

In March 2022, Birthrights commissioned a poll by Survation of 1,069 women and people who had given birth in the last five years in the UK. 556 respondents were white and 513 identified as Black (145), Asian (227) or Mixed ethnicity (141).

26% of Black, Asian and Mixed ethnicity women said English was not their first language, compared to 10% of white women. There was a similar spread of participants in both groups from across UK regions and nations, except for a higher proportion of Black, Asian and Mixed ethnicity women who gave birth in London. Similar proportions identified as LGBTQ+ in both groups. 38 respondents said their gender identity was not the same as the sex they were assigned at birth – 14 white, 4 Black, 11 Asian and 8 Mixed ethnicity.

There were no substantive differences within the sample in relation to mode or place of birth. On the whole, the majority of both groups reported experiencing respectful maternity care.

However, the findings underline the inquiry's evidence in relation to choice, informed-decision making, cultural needs and the direct impact of race on care.

Black, Asian and Mixed ethnicity women were more likely to report that they felt uncomfortable:

- Communicating their cultural preferences or requests
- Asking questions, because they didn't want their midwife or doctor to think they were being difficult
- Making decisions about their care, because they felt uneasy disagreeing with the care options the doctor or midwife recommended
- Choosing where to give birth, as they were not given enough information to make a decision

A third of Black, Asian and Mixed ethnicity women who reported they were treated poorly by their midwife or doctor felt that this was because of their race or ethnicity.

They were four times more likely to say this was the reason compared to white women, and twice as likely to feel it was because of their cultural background or language.

4. Findings and evidence

### 4. Findings and evidence Safety

### "They were panicking, and I thought I was going to die."

Participant, Yoruba speaking focus group

#### **Finding**

Feeling unsafe during maternity care was the most prominent theme in the testimonies we received, with two thirds of people who shared their stories describing not feeling safe some or all of the time. Participants in our inquiry told us that racism and racial discrimination had a direct impact on their sense of safety.

Human rights law protects the fundamental right to access safe, appropriate maternity care, which encompasses both physical and psychological safety. Yet existing research shows that Black, Asian and mixed ethnicity women experience far higher rates of unsafe outcomes, including death. Our evidence supports this research, showing that many Black and Brown people do not feel safe during their care, regardless of clinical outcome.

#### **Evidence**

Throughout the inquiry, the testimonies we gathered illustrated that Black and Brown people did not feel safe when they attended maternity care settings. Amongst the stories received, there were many that depicted experiences of women feeling deeply fearful, with the majority of respondents to the call for evidence saying explicitly that they did not feel safe throughout their maternity care. Many of the testimonies shared in the call for evidence, focus groups and interviews describe situations where the safety of women, birthing people, and their babies was impacted on by poor care, including racism and negligence related to race, sometimes with devastating outcomes. Interviews with legal professionals underlined this lack of physical and psychological safety, which has profound implications for human rights and racial equity.

#### Physical safety

Amongst the evidence gathered were examples of serious risks ('near misses') and actual harm being done to women, birthing people and their babies.

Examples are given in the case studies below. Some show how physical safety was compromised by failure to take concerns seriously or to spot lifethreatening symptoms in women, birthing people or babies. Others show that although their race was never explicitly referenced, their experiences left them questioning whether they would have encountered the same treatment had they been white.

#### Case study:

### Ghanaian person with life-threatening blood clot overlooked postnatally

One interviewee described their experience when being discharged home from the postnatal ward after repeatedly raising concerns about pain in their chest and feeling breathless. It was later discovered they had a pulmonary embolism, a life-threatening blood clot in the lungs. They describe the dismissal of their own and other Black women's voices, and in this case, the clear and direct impact on their safety.

"I was literally about to go home, there was a genuine 10 minute period between me going home with a potential embolism [and] it was just so weird, like the day before I remember constantly saying 'my chest feels really tight, I can't breathe, I can't stand, I can't walk, I can't do anything'. I had to get a bed pan to pee in because I couldn't stand for long without losing my breath and I'm like, you know I get it, I was anxious. But also, I genuinely couldn't breathe, you know, and that's the moment that always scares me because you hear so many of these stories, especially from Black women where their pain hasn't been taken seriously during this crucial moment. [...] My pain wasn't taken seriously and I was dismissed to the point that could have actually, you know, cost me my life."

#### Case study:

### African woman with sepsis dismissed during birth

One written testimony described a "horrible" birth experience where the midwife repeatedly minimised her concerns, continued with her paperwork and did not recognise the symptoms of sepsis, in this case paleness and loss of colour in the skin, due to her being a Black woman.

"I shivered so badly for quite a while that I thought I would die. When my husband asked for blankets, the nurse said it was a natural reaction and it would die down, eventually my husband searched all the room and found some blankets then covered me up."

She repeatedly raised concerns that she could feel severe pain despite the epidural. It was only when a South Asian doctor doing her rounds for the night finally noticed her skin was pale that swift action followed: "She took one look at me and asked if I felt well. I answered "not really, I feel like I have the flu" then she asked the nurse if she was checking my temperature which she replied "yes". The doctor was still concerned, she said the patient looks pale (I think she noticed this because she was South Asian) and asked the nurse to check my temperature again, it had soared!"

After being put on antibiotics and with an assisted delivery, she gave birth to a baby girl.

"I later learnt that I had suspected septicaemia and it was captured just in time with the antibiotics drip. I believe that doctor saved my life and my baby's life. I think if I were a white woman, my constant request to check my pain relief (epidural) would have been validated. I felt like [the nurse] thought I was either strong enough or I was exaggerating."

### 4. Findings and evidence Safety

There were multiple examples across the written evidence, focus groups and legal interviews of jaundice being missed in Black babies, which highlight how centring the 'white norm' in education and training directly impacts on the safety of Black and Brown women, birthing people and babies, jeopardising their basic human right to life under Article 2.

#### Case study:

### jaundice not recognised in a Black baby

"For my second child I had good birth care, he was premature. After we went home he developed jaundice. My health visitor was not convinced but my whole family could see it. She said she'd test his levels just to put my mind at ease. He tested super high and the HV was alarmed but she kept insisting the machine must be broken. She agreed to inform her superior though, still insisting there was nothing wrong but "mum wants some reassurance", and the superior agreed to refer us to the hospital.

"At the hospital the doctor admitted the reading was very high but insisted from the look of him there is nothing to suggest he was severely jaundiced, just a "slight" yellowing of his eyes. By then he looked neon to me. They did another reading and sent his bloods off, it was even higher than the last. My baby was immediately hospitalised for several weeks. The white staff did not recognise jaundice in a Black baby."

#### Serious harm and death

In the written call for evidence, over a third of stories described birth injuries such as severe tears, botched stitches, infections, postnatal haemorrhage or long-term incontinence. Just under a third described neonatal complications where the baby's life was in danger and/or they needed to be treated in intensive care. Baby loss, including miscarriage, stillbirth and neonatal deaths, was described in 12 written testimonies.

Testimony from solicitors and barristers representing families where a mother or baby has experienced serious injury or death emphasise the devastating consequences of this lack of safety. Other cases demonstrate the impact of negligent care on babies' outcomes and the psychological trauma it can cause. An Afghani woman giving birth during the Covid pandemic was denied pain relief and her concerns were ignored: she ultimately had a stillbirth. A British woman of African descent with high BMI and high risk of pre-eclampsia had poor care resulting in stillbirth. A Black woman was denied her choice of caesarean despite a history of haemorrhage and multiple miscarriages; she and her baby nearly died and she was left with "severe psychological injuries". The lawyers involved in these cases felt that race was a contributing factor to the mismanagement of these women's care.

#### Psychological safety

Psychological safety is a critical element of safe maternity care. Fear can have a profound physiological impact during pregnancy and birth, lead to people not accessing care, being unable to voice concerns about their care and suffering long-term psychological trauma. We heard from respondents that they felt fearful and unsafe during their maternity care, which led many of them to feel unable to raise concerns with their caregivers.

Not being listened to when you do speak up can also contribute to a lack of psychological safety. Many participants reported how frightening it was to feel as if your voice was not being heard at one of the most vulnerable moments in your life.

"There was one point in my labour right near the end where I remember looking at [my Partner] and saying, I'm going to be a Black statistic. I was so scared, and the epidural hadn't come so I felt like people weren't listening to me, it had been days..."

We received testimonies which described women and birthing people being shouted at or threatened, consent not being requested prior to medical interventions, and fear of reprisal from staff if concerns were raised or complaints made. These led to an environment of fear for women and birthing people.

Respondents described the long-lasting psychological impact of feeling unsafe. Studies have shown that fear and lack of control during birth are strongly associated with post traumatic stress disorder (PTSD).<sup>7273</sup>

"Refusal from [the Doctor] to provide informed consent and to proceed to shout at me during a Vaginal Examination made me feel unsafe after labour and whilst recovering on the maternity ward. I felt scared and anxious about encountering his observation again and I felt that myself and my baby's health and care were both at risk."

"[The Doctor's] actions resulted in me feeling very anxious regarding the intentions of the other staff that followed and the type of care and examinations that they would provide. I no longer felt safe or comfortable in the hospital, I wanted to be discharged as soon as possible and to resume my recovery and rest at home where I felt safe, secure and listened to."

<sup>&</sup>lt;sup>72</sup> Capik, A. and Durmaz, H., 2018 Fear of Childbirth, Postpartum Depression, and Birth-Related Variables as Predictors of Posttraumatic Stress Disorder After Childbirth

<sup>73</sup> Birth Trauma Association, undated, Post-Natal Post Traumatic Stress Disorder



### 4. Findings and evidence Being ignored and disbelieved

### "You speak and nobody hears."

- Solicitor, legal interview

#### **Finding**

We received numerous accounts from people who felt their voices were not heard during their maternity care. In particular, people reported that their pain was dismissed or minimised. There was evidence that the failure to listen to Black and Brown women and birthing people was at least in part a consequence of racism.

Failing to listen to people, disbelieving and dismissing their concerns, constitute serious failures to meet the legal standards set out in the Montgomery case and under the Human Rights Act. It is essential that caregivers establish respectful relationships with the people in their care and respond appropriately to their concerns.

#### **Evidence**

Over half of respondents to the call for evidence gave an example of being ignored or disbelieved when they had concerns about their health or the health of their baby. Many women reported their concerns or requests around provision of care or the type of care they could access being minimised.

In some examples given within the inquiry, the racial element was explicit and the role of racist stereotypes in creating a culture in which women's voices were not listened to was obvious. One midwife from a focus group spoke about two separate occasions where Asian women were disbelieved due to racist stereotypes, a belief that Asian women can't handle pain and 'make a fuss', and so did not receive pain relief or the appropriate care that either of them needed –

"[An Asian woman] laboured without pain relief, having been dismissed as being, as making a fuss."

"... She was Asian. [I wanted to go and see her] but I was told she was making a big fuss. ... And it ended up with her giving birth in the lift on her way to the labour ward because she was clearly in advanced labour."

Another midwife who was interviewed spoke of their own experience and the shared experience they had with other ethnic minority parents –

"And honestly, all [of our] stories were very, very similar, they're not listening to us, they told me I had to do this, I didn't know I could say no. Some mums were asking for pain relief for hours, [but] were not given it. Other mums, they were just basic requests, like simple, simple things like I just wanted my sister to come in and give me my bag so I could see her."

A Sikh woman described feeling ignored when she raised concerns about her baby's feeding, due to stereotypes linked to her religious dress –

"During the postnatal stage, I was telling the nurses she wasn't latching and was bringing up some yellow fluid. I was dismissed at first and then they assessed and took her to neonatal. There were too many incidents of not being taken seriously and my worries not being validated. I feel race probably played a part as I am a turban-wearing Sikh so look very different."

The interviews with LGBTQ+ people, discussed with the panel in the oral evidence sessions, echoed these findings and emphasised that people did not feel listened to.

#### Disbelieving pain or contractions

One of the most common experiences described in the testimonies we received was that of Black, Brown and Mixed ethnicity women and birthing people's pain being ignored or denied, and of pain relief being withheld due to staff not believing they were in labour. Almost half of written stories detailed pain relief being denied or delayed. Failure to take Black women's pain seriously has a long history in maternity care, as the evidence in our literature review shows. The testimonies we heard show that the legacies of racism in the treatment of Black women continue to have an effect today.

Our inquiry found that racist stereotypes, including about Black women's perceived ability to tolerate pain and Asian women's perceived inability to cope with pain, are having a significant impact on women and birthing people using maternity services.

"Every hour I repeated to them that I wanted an epidural because I feel very tired, I can't go ahead, but they just left me after... and they didn't do anything for me".

### 4. Findings and evidence Being ignored and disbelieved

#### Case study:

### pain and contractions not being believed

A Chinese woman attended hospital a day before her due date with some bleeding, but was discharged and told to stay at home even after contractions started. The pain was so severe she took a taxi to the hospital and had to resist the urge to push. When she arrived the staff were angry that she had come back. She was told to wait where she was even though she could barely stand. When she was examined, she was 8-9cm dilated.

"I started to have a great pain, I felt the induction pain and I was screaming. Unfortunately, the midwife didn't really believe me, she was like 'how are you having the pain with you having an epidural?' She didn't believe me, she didn't act as though she believed me and I was having great pain. Then after me screaming and shouting, they asked for the doctor to check my epidural and when he poured cold water on my legs, I felt it."

"I kept asking them to give me strong painkillers because my stitches were not dissolvable and they had to remove them after five days and it's the c-section stitches that got really infected and my wound started bleeding. So I was in a lot of pain, but they were completely refusing to give me strong painkillers."

#### Dismissing serious concerns

The inquiry found that women and birthing people raised concerns about either themselves or their babies to healthcare professionals, only to have their fears dismissed or belittled. Similar to the findings of the Ockenden report, 4 we found that there were situations where significant harm could have been avoided if people were listened to and concerns were investigated at the time of being raised, rather than being brushed aside.

A midwife spoke of an experience where she came on shift to find a Black African woman who had been lying in pain for hours, after requesting help and pain relief and receiving none, nor any examination. It later resulted in her being transferred to theatre where it was discovered that she was bleeding internally.

"And I went into the room just when you do the rounds, you know say hello to all your patients and she was just lying in absolute agony and saying that I'm in all sorts of pain and someone help me, and she'd been lying there for hours and been saying that she was in a lot of pain and hadn't had any painkillers and hadn't had anyone look at her or anything like that. And in the end, they pushed away into the operating room, and she had an internal bleed."

Another participant from a focus group recounts asking the midwife to make the room a bit warmer as she was concerned about the temperature of the baby, but her request was refused. The baby then needed assessment by a paediatrician.

"I said, 'This baby is going to be cold.' Do you know what happened next? In another 20 minutes, they said, 'She is not responding. [Baby] is not responding.'"

#### Case study:

### dismissing concerns about jaundice leading to harm

A clinical negligence solicitor shared how a Black woman's concerns over her baby having jaundice and looking yellow were overlooked and "totally dismissed", resulting in the baby becoming brain damaged. "The baby started being extremely poorly and so by the third day she'd had no support and no help, [she was] really worried about her. And you know, the damage had been done. She had hyperbilirubinemia and she's got cerebral palsy."

The solicitor expressed frustration about the failure to listen to her client's concerns and prevent avoidable harm.

"Like check the baby, the mum's saying she's worried about her being yellow, why are you not all over that? And she's a beautiful little girl, but she's got a lot of complex needs now and that [was] totally avoidable..."

<sup>&</sup>lt;sup>74</sup> Department of Health and Social Care, 2022, Final report of the Ockenden review



### 4. Findings and evidence Racism by caregivers

"Whether racism is unconscious or conscious, indirect or direct, intentional or unintentional, or persistent from institutions, the impact is the same."

- Nova Reid, The Good Ally

#### **Finding**

We found that racist attitudes and behaviours by caregivers – manifesting as stereotypes, microaggressions and assumptions about risk based on race – are having a serious detrimental effect on people's maternity experiences. Two thirds of respondents to our written call for evidence felt that their race, ethnicity or religion impacted on their care. In the Survation poll, 31% of Black, Asian and Mixed ethnicity respondents who said they were treated poorly by their midwife or doctor felt that this was because of their race or ethnicity.

Racism is a fundamental violation of the right to be treated without discrimination, protected by both the Human Rights Act and the Equality Act 2010. As well as being unlawful, our evidence suggests that racism plays a part in the inequalities in health outcomes for mothers and infants. Crucially, it is the persistent and prolonged exposure to microaggressions that causes harm.

#### **Evidence**

#### Stereotyping and microaggressions

Almost half the respondents to the written call for evidence described experiencing racial microaggressions, stereotypes or assumptions – leading to distress and trauma.

Stereotypes are preconceived ideas about a social group that can lead to limiting beliefs and dangerous misconceptions, which can be very damaging. Microaggressions are "the everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, which communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalised group membership".75 Although racial microaggressions may not always be consciously racist, they show a thoughtlessness for other races, cultures and identities and often centre the white perspective as the norm, for example failing to learn the correct pronunciation of someone's name. Repeated exposure to microaggressions compounds trauma and harm.

<sup>&</sup>lt;sup>75</sup> Sue, D.W., undated, Microaggression: More Than Just Race

### 4. Findings and evidence Racism by caregivers

Although we will use these words in this chapter, as they are used by women, birthing people and professionals within the evidence, we recognise that describing racist behaviour with this terminology can obscure and minimise the damage it causes and can reduce accountability for those who perpetuate this behaviour. Stereotyping and microaggressions are forms of racism and we recognise them in this way and the harms they cause.

From the evidence we gathered, it is clear how damaging these stereotypes can be, subjecting women and birthing people to degrading treatment and putting their and their babies' lives at risk due to dangerous racist misconceptions. In a healthcare setting, even seemingly 'small' errors based on preconceived ideas around race and identity can have serious consequences.

Throughout the written testimonies, focus groups and interviews, there were a multitude of accounts where women and staff had heard Asian women being referred to as 'princesses' or 'precious' and Black women as 'aggressive' or 'angry'.

There were multiple reports of healthcare professionals repeatedly asking "where are you from?", not trying to pronounce names correctly and of misidentification based on assumptions of race and perceived ethnicity. One woman told of her experience going for an ultrasound scan, where the sonographer did not double check her name against her notes leading her to perform the wrong scan on the patient –

"At that moment, she went mad at me like, 'you're not Batul, you're not Hadija, you misled me in this appointment, I need to do everything again.' [...] At some point I told her 'it's not my fault, it's your fault, you didn't recheck my name and my date of birth and my details when I came in, you just started scanning [...] So she said sorry, she was saying to me my name is difficult, that was why the problem happened."

Women also reported numerous examples of direct incorrect assumptions being made about educational status, domestic violence, marital status (as assumed Black women are single mothers), Muslim women having lots of children and Hijabwearing women not being able to speak English. People frequently reported feeling patronised and othered due to assumptions based on race –

"I wore my hijab and abaya during my stay at hospital. Staff in the special care unit were very patronising [until] I disclosed that I was a pharmacist, [when] the whole team's behaviour changed." The descriptions of these in testimonies from women and birthing people supported the recent findings of MBRRACE's review of maternal deaths, which particularly noted microaggressions towards Asian women.

Even stereotypes around certain ethnic groups that are framed in a positive way can still have a negative impact. Women reported feeling as if it was assumed that because they were Black or Brown they would know how to breastfeed or have a lot of family support who would help with feeding and in the early postpartum days, with one woman being told "you African women know what you are doing". This led to women finding it difficult to get the support they needed from staff and often having issues with feeding, which in some cases resulted in serious complications for their infants and impacted on women's mental health.

Healthcare professionals reported hearing the same stereotypes about family networks from their colleagues, which they said led to a lack of postnatal support for people in their care –

"...women from ethnic communities, especially Asian, and I assume it's similar to Black communities, there's this understanding or people believe she's got lots of family, so she's not going to need any help with breastfeeding, you know she's going to figure it out."

In the oral evidence sessions, the panel emphasised that healthcare professionals can fail to recognise that they are using stereotypes or microaggressions and believe that they "treat everyone the same" or that they are "colour blind".

#### 'High risk' bodies

"There's also this assumption that we're going to have these problems even if we don't."

There were many accounts of women and birthing people being put into the high-risk category due to factors relating to ethnicity, leading to the pregnancy and childbirth experience being overmedicalised. In some cases, these decisions seemed to be based on skin colour and assumptions about risk, rather than observed medical indications.

One person recounted their experience, repeatedly being told they were at high risk of having gestational diabetes due to being Black and overweight, and being told to come in for weekly blood pressure monitoring despite her blood pressure and diabetic screening bloods always being within normal range –

"I have a feeling that they're really angling and they're going to try and tell me I need to be induced, or need some kind of intervention. [...] I keep asking 'can we talk about my birth plan and what my options are'. And I keep getting told, 'no, because you might be high risk'."

These testimonies aligned with the panel's discussion with NICE about the inducing labour guideline, which singled out Black and Brown people for routine induction without a robust evidence base.

Other accounts demonstrated how perceptions of risk based solely on ethnicity or genetics can lead to racist outcomes within both individual care and Trust policies –

### 4. Findings and evidence Racism by caregivers

"[The hospital where I worked] had an induction of labour for ethnicity as a [reason] that was written down. And when I challenged that and went to the coordinator and said, the consultant's put down, this woman doesn't even know why she's here but when I've looked on the screen to see why she's been booked in for induction, it says ethnicity and that's not a thing, that's not a reason for an induction, there's nothing else in the background that I can find. And the coordinator said 'just don't challenge it'."

These accounts show the over-surveillance of Black, Brown and Mixed ethnicity women and birthing people by maternity staff. The evidence in this inquiry underscores the invisibility/hypervisibility paradox for people from ethnic minorities, where on one hand their bodies are pathologized as a result of their skin colour, but when they wish to voice their own views about their care, they are not heard.

In line with this feeling of 'invisibility', there were multiple accounts of conditions or symptoms not being recognised in Black and Brown women and their babies due to the colour of their skin and misconceptions about how certain illnesses present in people with darker skin.

"I once worked with a midwife who told me that Black women don't bruise, and I thought that's one of the most dangerous things that I've ever heard coming from a healthcare professional [...] what kinds of things are you missing in your patients."

As set out in the chapter on safety, this failure can lead to serious consequences, for example when life-threatening conditions like sepsis are not picked up early.

Healthcare professionals in the oral evidence sessions and on the inquiry panel made many references to the way in which midwives and obstetricians are trained, with an emphasis on the curriculum and how it is often centred on the white body as the norm. A midwife in the focus group summed it up –

"We need to learn more about Black people, [all] the textbooks are [based on] white men, you know physiology and anatomy and everything like that, so we need more information, evidence about that."

In the oral evidence sessions with the Royal Colleges, Nursing and Midwifery Council and NICE, there was consensus about the need to decolonise education and clinical guidance. Many healthcare professionals felt that there needed to be more education on the specific conditions that affect certain ethnic groups, delivered in a way that does not pathologize Black and Brown bodies, included within the midwifery and medical curriculum. Education on cultural safety, woven into the midwifery curriculum in a more applied way, was also highlighted as a priority. The expert panel flagged the example of New Zealand, where cultural safety is embedded in midwifery registration and revalidation.

#### **Cultural insensitivities**

There were many accounts of cultural insensitivities and failures to respect the cultural needs of service users. Very few women described being asked about their cultural or religious needs. In the Survation poll, 14% of Black, Asian and Mixed ethnicity respondents who said they were treated poorly by their midwife or doctor felt it was because of their cultural background or language – they were almost two times more likely to say this was the reason than white women. Professionals reported some of their colleagues ignoring or ridiculing cultural maternity practices.

#### Case studies: lack of respect for cultural needs

An Asian woman told staff that the milk provided was not suitable for her baby and her husband would be bringing Halal milk – she then overheard staff saying "'people like me' have made issues like this in the past", which was deeply upsetting.

A woman of Chinese descent spoke of how staff appeared shocked and made her feel embarrassed about not showering immediately after delivery, due to wanting to follow traditional Chinese post-partum customs. This disrespectful practice contravenes much of the guidance outlined by clinical regulatory bodies such as the NMC <sup>76</sup> and Royal College of Obstetricians and Gynaecologists (RCOG), <sup>77</sup> as well as NHS guidance, <sup>78</sup> which all promote an individualised or person-centred approach.

#### Overt racism

Some women were subject to overt incidents of racism. One participant from Ecuador was told, whilst in labour, that she would need to learn English if she wanted to live in this country. Another participant recounts being told she must give her baby the BCG vaccine due to being from Africa –

"They always say it like that. 'Oh, we have to check for TB because you people coming from Africa are exposed to this...' I said, 'Excuse me, do you have to put it like that?' [She said] Yes, it's like people from Africa and minorities [...] because you live together."

Healthcare professionals described colleagues saying that Black women and babies have "thick, tough skin", that a ward "smells of curry" when South Asian families were being cared for, and that Chinese people are "dirty". They also observed Black and Brown women and birthing people experiencing differential treatment compared to their white counterparts – such as white women being allowed visitors out of hours, receiving more responsive care, being granted time for multiple questions and given more patience listening to concerns.

<sup>&</sup>lt;sup>76</sup> Nursing and Midwifery Council, Person-centred care

<sup>77</sup> Royal College of Obstetricians and Gynaecologists, 2021, RCOG responds to latest MBRRACE-UK Maternal report

<sup>&</sup>lt;sup>78</sup> Health Education England, Person-centred care

### 4. Findings and evidence Dehumanisation

"So and I think tied up in that is when you go into hospital and you've got the stripy nighty on [and] you are almost dehumanised. So they don't see you as [a woman, or a lawyer] what they see is a Black woman in the bed."

- Lawyer, legal interviews

#### **Finding**

Black, Brown and Mixed ethnicity people are subject to dehumanisation in maternity care, manifested by disrespect, rudeness and lack of empathy that breaches basic human rights principles of dignity and respect.

The feeling of not being seen as an individual, or even as human, can act as a significant barrier to accessing maternity care, further entrenching the inequalities seen in outcomes and patient experience, and causing long-lasting trauma.

#### **Evidence**

A majority of responses to the written call for evidence described a lack of basic dignity, disrespect or rudeness. Stories shared in focus groups and by lawyers demonstrated a pervasive lack of curiosity or empathy, harsh or rough treatment, and even shouting and threats.

One midwife commented on how the entrenched view of Black and Brown bodies being deemed as 'other', often leads to them being dehumanised and pathologized.

"One of the things that's really embedded in this system is the blame that's put on Black bodies and that, you know this is somehow our fault because our bodies don't work in the correct way. I was taught as a midwifery student about the African pelvis and the problems that it causes that African women, Black women are more likely to have diabetes, that we're going to have high blood pressure, this is our fault, it's the food that we eat, it's the weight that we carry. Everything works against us that Black bodies and Brown bodies are basically flawed in some kind of a way and so that anything, any care that we're given, we should be grateful for."

As referred to in previous chapters, these contradictory beliefs around Black bodies being both defective at the same time as stronger, tougher, and able to endure more pain, are based on racist stereotypes which have their origins in slavery and eugenicist theory.<sup>79</sup> They were referred to on multiple occasions in the evidence collected, in the form of the 'strong Black woman' trope.

One Black woman was told "women like you" don't need pain relief and advised not to make so much noise. Conversely, many Asian women, particularly those of South-Asian heritage, referenced the 'princess' stereotype and healthcare professionals reported that women from these backgrounds were perceived as 'precious', less able to tolerate pain, and often 'made a fuss'.

#### Disrespectful care

"As a Black woman I felt less than human. I was dictated to, not asked."

Many of the stories shared in focus groups and interviews described Black and Brown women and birthing people being subjected to a lack of basic dignity and respect, such as rudeness, and failing to honour cultural practices or requests.

Both women and staff reported women being made to feel like a burden, shouting, eye-rolling and even overt threats – such as one participant who was berated for co-sleeping – "[They said] 'If you do it again I will report you to social services and they will take the baby from you because you're not taking proper care of the baby, you're not keeping her in the cot. You can't keep her next to you on the bed', which is understandable but she didn't explain properly and she was really rude to me."

Women experienced intrusive or aggressive questioning during intimate procedures, such as being shouted at by a doctor during a vaginal examination, or facing invasive questions about immigration status while partially undressed.

A woman reported being refused a bed pan during labour –

"When I was in labour, I told the nurse to give me a pan so that I could go and pee, she refused... I'm not absolutely sure [if it was because of my skin colour but] after that incident, I felt really sad during the labour."

The evidence highlights how a lack of respect and empathy, which may be racially motivated, can leave women and birthing people feeling disrespected and unsafe. Black and Brown women and birthing people told us they asked themselves whether they would be subject to the same treatment if they were white?

<sup>&</sup>lt;sup>79</sup> National Human Genome Research Institute, Factsheet: Eugenics and Scientific Racism

### 4. Findings and evidence **Dehumanisation**

#### Neglectful care

Lack of empathy also manifested in reports of poor care, where women were left in vulnerable states or inappropriate conditions. There were also reports that they or their partners were not given important information regarding their care or the wellbeing of their child.

Lawyers we interviewed described insensitive attitudes in stillbirth or injury cases and they detected bias compared to records in white women's maternity notes.

"There was correspondence between the midwives that we received when we had made our application for medical records.

And it was so dismissive [...] it was unusually phrased certainly and quite...harsh. [...]

usually when a mother's been bereaved, they're very sensitive [...] I felt like it was showing some sort of bias towards her, the attitude that I saw in those records."

A clinical negligence solicitor described a case that underlines the lack of empathy and failure to uphold basic human dignity, where a woman labouring alone was left without support of any kind from caregivers –

"Over the night, she started feeling very, very unwell. She was asking for help, totally ignored. Really painful contractions, not given any pain relief. ... she vomited on herself, she wasn't helped to get clean. Told to go to the shower by herself. All the time she's texting her husband because he couldn't be there. ... she thought she was going to die."

#### Case study:

#### lack of respect and empathy

One interviewee reported two incidents, firstly where they attended hospital for an induction of labour to be left waiting for hours without any explanation –

"When I came in for my induction, there wasn't a bed ready. So, I was basically sat in this empty bay. Just waiting and then they forgot about me, for like four hours, so then some random person was like [...] 'what are you doing here?' And I was like 'we were told to wait here four hours ago. But my name is {name}, I was booked in for an induction' and she was like, 'oh sh\*t, I'm so sorry'. So, then they finally got me a bed. We paid for a private room because I've got agoraphobia, didn't get the private room...and then I went, and the private room was empty, so annoying. So, I was like the room was empty and I paid

for it and I'm still not getting it, what is that about? But yes, it was very, very traumatic."

After having had their baby, this person then developed a blood clot. When returning from a CT scan they were met with a midwife refusing to accept them into their bay –

"I went to have this CT and then I came back, and I was being put back into my bay and then a woman was like, no she can't come here. I'm full, so basically they had moved my bed. And then it was like, okay this porter didn't really know where to take me so took me to another bay, they were like, no, no, no, I'm done, I don't want anymore. And it was really horrible, I literally just found out that I had a clot in my lung, and I was just being moved around from bay to bay with people saying, no, I don't have enough beds, I'm trying to get all my people discharged. And that felt quite cold and it was quite upsetting."



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### 4. Findings and evidence Choice, consent and coercion

"All the stories were very, very similar, they're not listening to us, they told me I had to do this, I didn't know I could say no."

- Black LGBTQ+ interview participant

"Number one has to be making sure that no matter what language you speak, you are still given a thorough and clear indication of what any risks are, and to make sure that you understand that [...] I think a lot of people can just be pressured into ticking something to say that they've understood it when they haven't."

Lawyer, legal interviews

#### Finding

We found serious and routine violations of the right to informed consent for Black, Brown and Mixed ethnicity people. The evidence showed that consent was not always sought for medical procedures, caregivers sometimes used coercion and obstetric violence, and there was a lack of choice about their maternity care.

These findings reveal a maternity service struggling to serve women, birthing people and families, or to support its staff. They are not unique to Black, Brown and Mixed ethnicity people's experience, as we have seen from the Ockenden report. However, they are even more dangerous when combined with systemic racism, as they reinforce inequalities and cement feelings amongst Black, Brown and Mixed ethnicity women and birthing people that they are unsafe within the maternity system.

#### **Evidence**

A majority of written testimonies said they did not have choices explained or respected, and only a third experienced clear, accessible communication. Multiple accounts from women, healthcare professionals and lawyers described very serious instances of coercion or obstetric violence. This had a profound effect on Black, Brown and Mixed ethnicity women and birthing people's experiences of pregnancy, birth and postnatal care. The traumatic nature of these events can have an impact on maternal mental health.

#### Lack of informed decision-making or consent

Many women reported that staff failed to gain consent prior to interventions such as vaginal examinations and membrane sweeps, giving medications and injections, or before operations such as caesareans or instrumental births such as with forceps.

Respondents repeatedly said they felt as if they had no control and that things were being 'done to them', they were not encouraged or asked to share their opinion, and some felt unable to speak up.

"It was very, 'we need to do this, we need to do that', rather than, 'this is what we think we should do, and this is why we need to do it'. It was very much; 'you've just got to do this'. And had I not had those sessions with the doula, I would have gone [along with it] because that's how they make you feel, like you don't know anything, they know best. [...] I just felt, the respect in terms of what we wanted wasn't there."

"I kept asking if I could go to labour ward or birth centre and was told there was no room. At 6.30am I was checked, told I was probably going to have baby around lunch time, [but] baby came half an hour later. When he was delivered I felt a stab in my leg and the midwife had injected me with something. When I asked what it was, she said it was to help with delivering the afterbirth. I had requested not to have this injection but was not asked before it was given. The first I knew was feeling the needle in my leg. I felt that throughout it all I was not listened to fully [...] and not trusted to know what was happening to me. I knew when my baby was coming, but wasn't believed, I knew that my contractions were unnaturally close during induction and ignored. It took me a long time to not feel rage about the whole experience."

#### Case study:

### failure to provide interpreter jeopardising consent

In one legal case, a solicitor described the experience of a woman whose request for no male staff and to have female interpreters was denied. They instead allowed her sister-in-law to translate, who was not a trained interpreter, which led to a lack of informed consent for vaginal birth after caesarean. The internal investigation found if her wishes had been listened to and she was allowed to have someone translating for her, the hospital would have known she didn't understand or didn't have enough information to give consent.

The lack of translation or interpreting services also played a significant role in this.

There were many examples of women with limited or no English who had no access to an interpreter or adequate translation services, leading to them having procedures where they were not clear of the risks or benefits, or even why they were having it all.

<sup>&</sup>lt;sup>80</sup> NHS England and Improvement, 2022, Ockenden final report letter to NHS Trusts

### 4. Findings and evidence Choice, consent and coercion

#### Denying choice

There were many examples of women being denied choice by simply not having their options explained to them, either in a way they understood or not explained at all.

"I don't believe I was communicated to clearly by healthcare professionals, and in a way that I could understand. Everything was a tick-box exercise. Nothing was tailored. I was not asked about my cultural needs. I was not told about my options, and when I asked for pain relief, it was not given to me."

"They didn't give me any other options, not once did they tell me any of the risks of doing something or not doing something."

One participant from a focus group was asked whether anyone had ever discussed the options for place of birth, her response was "No. Never." This was echoed throughout the evidence. In other examples, choices were actively undermined or refused. Others faced resistance to their preferences and came under substantial pressure e.g. to be induced, to have a caesarean, or not to birth at home. Some examples related to the choices women made about their care not being listened to.

### Case study: pressure to be induced

One woman spoke of her request for a homebirth being dismissed, as she was told she would need an induction of labour. She tried to arrange a discussion to weigh up the risks and benefits of an induction and look at other options to better understand and make an informed decision. Despite these requests for a discussion, which she repeatedly made from early on in her pregnancy, it did not happen until she was 37 weeks pregnant and even after making her decision to have a homebirth, she received daily phone calls asking her to come in for an induction.

Another participant, despite having written a birth plan and communicating the request for the midwives to only speak to their partner during labour, had this request completely ignored during their labour, which caused her significant distress.

#### Coercion and obstetric violence

Obstetric violence is "verbal, physical, psychological, and institutional abuse that occurs (usually in healthcare settings) during pregnancy and birth", with racist, sexist and misogynistic roots. It can include being forcefully held down, physically pushed, or nonconsensual examinations and procedures, which were all described in the inquiry evidence. Verbal or physical coercion overrides consent and violates the right to autonomy. Page 2015.

Our evidence found that Black, Brown and Mixed ethnicity women and birthing people experienced both coercion and obstetric violence on multiple occasions throughout their care, and felt their ethnicity caused or played a significant factor in these scenarios.

One of the most common examples of this was women being given vaginal examinations without consenting to them –

"I was not given informed consent during a Vaginal Examination from [my doctor]. No form of suitable communication was given. I felt I was abused by his conduct and his reaction towards me. It was very unprofessional and no remedy [or] sympathy towards me, my concerns or feelings were given [...] I believe that [my doctor's] behaviour is a reaction more commonly linked to my race rather than my gender. [...] his temperament towards me and his aggressive nature and disbelief when I showed signs of discomfort and pain and spoke out about it, made me feel

that he was not in belief or even held the slightest consideration and concern about my pain and how I was feeling. This is a common attitude I have come to learn is prevalent in medical practices, that ethnic Minorities (particularly Black African and Caribbean People) do not feel pain or have a high tolerance to pain, which would explain why [my doctor] posed an alarming reaction when I exhibited that I was in pain."

"My first 3 pregnancies, I used the NHS. Consent was [not gained] from me, [there was | bullying, misinformation and a presumption that I was uneducated and naive. During my deliveries I have had midwives carry out procedures... I was left battered and bruised and no one did anything to protect me. [...] I had a late miscarriage, the result of DV [domestic violence], I had strange men put their hands in me, I didn't know who they were as they didn't bother to introduce themselves or talk to me at all. I now know that they were doctors. I was terrified, alone, bruised and battered. With my last two children [...] I used 'Private Midwives'. Entirely different experience, [there was] consent, care and I felt safe."

Other examples included being physically forced to undergo interventions that women had explicitly not consented to. A lawyer described an Asian woman who "made it clear that she didn't want a forceps delivery. She's very smart, she's very educated, she knew what she wanted and said all of this. And she was literally pinned down by a consultant and you know, she got a tear from it, her little baby got a forceps scar and she was absolutely traumatised by the whole thing."

<sup>81</sup> Durham University, 2021, The Battle for Recognition: Obstetric Violence and its Long Controversies

<sup>82</sup> Birthrights Factsheet, Consent: the key facts

### 4. Findings and evidence Choice, consent and coercion

Verbal and psychological coercion was also commonplace, particularly when it came to women who chose to birth outside of NHS Trusts' guidelines. There were many examples of women feeling that their requests weren't listened to or supported, and who faced substantial pressure, despite them making an informed decision about their care –

"I felt pressured by the doctors to have a hospital birth due to having a previous c-section. My midwife made me feel extremely uncomfortable with the decision I had made to have my birth partner and doula there during the pandemic, she made me feel as if I was putting the midwives at risk despite the precautions we had all undertaken to keep everyone safe. During my pregnancy I felt there was a lack of empathy from her which made me feel uncomfortable, she also wouldn't respond to some of my messages and concerns and instead the midwife in her absence was a lot more supportive and helpful towards me and my situation. During my labour, the doctor pressured my husband and I to go for an induction despite the discussion of me wanting a home birth. I wanted to wait a maximum of 48 hours after my waters had broken, which was against their policy of 18 hours and so my husband and I were made to feel as if we were putting our baby at risk and could "kill" him... After surgery I overheard the anaesthetist visit a white woman who had just had surgery ensuring she's ok and asked how she felt. I was not given this type of care."

#### Continuity of carer

Continuity of carer was discussed within some of the inquiry focus groups. Many participants expressed a wish that they had seen a consistent midwife through their care:

"I found that really, really hard, I can't remember how many different midwives I sort of spoke to and saw, six, maybe seven."

"Because I was seeing someone different every time it was, you know, everyone I saw was polite and friendly and doing the absolute best that they could do, it felt like there was always that element of catch up because it was a very quick appointment."

Others who did have continuity highlighted some of the challenges. One participant felt that although she saw the same midwife, she was so busy and overstretched she barely knew her name, didn't listen when she disclosed anxiety and just offered a phone number to call. Another was never asked about mental health at any of her antenatal appointments.

The expert panel also highlighted the risk of continuity of carer being problematic if a midwife is racially discriminatory and emphasised the importance of the right to change your caregiver, without having to give a reason,<sup>83</sup> and of anti-racism training for all maternity staff.

<sup>83</sup> Birthrights Factsheet, Your right to choose your midwife and doctor

# 4. Findings and evidence Structural barriers

### "People are dying because they don't want to go to hospital."

Participant, Yoruba/English speaking focus group

#### **Finding**

There are two main structural barriers to safe, respectful and non-discriminatory maternity care: lack of access to interpreting services and the impact of NHS charging. These structural barriers disproportionately affect Black, Brown, and Mixed ethnicity women, particularly those who speak English as a second language or who have refugee, migrant, or asylum seeker status. They pose serious risks to people's safety and dignity in maternity care.

#### **Evidence**

#### Interpretation services

The lack, or failure, of interpretation services was a common theme discussed in many of the focus groups and legal interviews. Trusts have a duty of care to ensure effective communication for all patients, which includes meeting their language needs by providing adequate interpretation services for all elements of their care.84 Failure to provide such support is a significant barrier to communication, hindering the ability of healthcare professionals to provide information and the individual's ability to make informed decisions and to give valid consent. Lack of interpreting services therefore directly threatens the human right to bodily autonomy. This disproportionately impacts on Black, Brown and Mixed ethnicity women with little or no English.

We heard multiple accounts of women not receiving appropriate or timely interpretation and translation services, despite requesting it. One woman requested an interpreter for her appointment but was told it was too expensive at a rate of £50 an hour, and as they could be needed all day, it was a "waste of public money". There were many accounts of healthcare professionals using inappropriate methods to communicate, such as Google Translate or relying on relatives as informal interpreters, including children. Birthrights has previously highlighted how such methods along with

the 'patchy' translation services, which vary from trust to trust, can be a threat to the clinical safety of women and their babies.85

In one of the legal interviews, the solicitor recounted a case where a woman's husband acted as the interpreter, resulting in important medical information that he was unaware of not being identified.

"So there was a problem about getting an accurate history. As a consequence of that, the doctors weren't told about her attendance in Mogadishu with suspected TB, [as her partner] didn't know about this because he met her while she had arrived in Britain. The problem about using him as the interpreter was there is a huge cultural sensitivity in Somalia about TB because it is thought to be a disease of poverty."

This highlights the problems that can arise when using family members as interpreters and the need for specially trained interpreters with knowledge in both women's health and cultural safety. Many of the legal experts we interviewed referred to the poor translation services playing a significant part in negligent care. There were multiple examples of legal cases where lack of interpreting meant no valid consent, and others where it led to serious harm to women or their babies.

#### Case study:

## lack of interpreting leading to infant brain injury

In one tragic case shared by a lawyer, a baby suffered a catastrophic brain injury due to hypoglycaemia caused by lack of feeding support, which she was unable to receive as no interpretation services were provided either antenatally or postnatally. The NHS Trust lost the case and had to pay out a significant sum in damages to the family.

"At the beginning of the antenatal notes, it said on page one of the records, 'Does she need an interpreter?' And the answer was, 'Yes' and [in subsequent entries] the little tick box section of the form had been ticked in [and someone] had written in capitals with stars all round it, 'This woman speaks no English. She must have an interpreter', and an interpreter was never provided. [...] [It states] in the NICE guidance [that there are two appointments] at which advice should be given on how to breastfeed. On the first, there was rather an elusive entry in the midwife record saying, 'Unable to give advice, no interpreter.'"

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<sup>&</sup>lt;sup>84</sup> Office for Health Improvement and Disparities, 2021, Language interpreting and translation: migrant health guide

 $<sup>^{85}</sup>$  Birthrights and Birth Companions, 2019, Holding it all together – executive summary

# 4. Findings and evidence Structural barriers

#### NHS charging for migrant, asylumseeking and refugee women

There were multiple accounts in the inquiry evidence that reveal how the NHS charging scheme for overseas visitors system discriminates against some of the most vulnerable women and birthing people within our society by limiting and preventing access to maternity care. We heard of women being told to pay charges before receiving any care. This included racial profiling, where British-born Black and Brown women were asked if they need to pay for treatment based on their ethnicity or appearance e.g. skin colour or religious dress.

There were many examples, including from healthcare professionals, of women disengaging with care or delaying attending due to fears about immigration status and not being able to afford charges.

#### Case study:

## refusal to provide care due to NHS charging

One woman experienced bleeding in early pregnancy so attended a GP where she was not registered and was told she would have to pay £220 for an ultrasound scan upfront. She said did not have money then and asked them to scan her and provide an invoice so she could pay later. She was denied an ultrasound unless she paid upfront, so she did not have it. She bled two further times after that but didn't bother seeking assistance as she had no money to pay for any investigations and was not told how to go about accessing any health care provision.

Others told us about receiving letters and demands to pay hundreds or thousands of pounds for routine maternity care. Consistent with the evidence we heard from Maternity Action, women were often told incorrect information by healthcare professionals or overseas visitor officers regarding payment and who is entitled to free NHS care, due to poor training and unclear Trust guidance. The circulation of this misinformation is deeply concerning and leads to women and birthing people at best, feeling stressed and anxious throughout their pregnancies, and at worse feeling unable to access the care they so vitally need:

"People are traumatised, they are frightened already, they don't need to go to hospital and be frightened more."

An asylum-seeker received a letter from the NHS stating that she has to pay £5,500 when she goes into labour, "even though she was trying to explain that I'm an asylum seeker and she says 'I was struggling'."

Another woman seeking asylum was disbelieved and required to pay for a c-section: "We don't believe the asylum and you have to pay."

Threats of referral to the Home Office by healthcare professionals when women attended hospital or when they failed to pay were also common –

"'If you are not going to pay the money then probably you will be in trouble. Maybe the Home Office will come to know about this and you will have some problems, they will send you back', these kinds of things they have started telling to me."

Other structural barriers shared with the inquiry included:

- Lack of availability of services based on location, e.g. no diabetic clinic at a local hospital, meaning women have to travel a greater distance to a larger hospital for their appointments. As gestational diabetes is more prevalent amongst certain ethnic groups, this lack of provision has a greater effect on ethnic minorities.
- Poor governance pathways, e.g. failing to record ethnicity/no uniform approach to recording demographics throughout the UK, failing to record and report serious incidents.
- Clinical policies that are not evidence-based.
- Lack of flexibility with appointment times and locations.
- Limited resources in other languages (such as information leaflets).
- Lack of antenatal education delivered in a culturally sensitive way (or in alternative languages).

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# 4. Findings and evidence Workforce representation and culture

"Tiredness and burnout do not cause racism. Racism does. However, tiredness and burnout means uncivil behaviour and unaddressed prejudice and racism are more likely to surface in daily interactions, which have a direct consequence on outcomes."

- Nova Reid

### **Finding**

Racism and discrimination deeply affects the maternity workforce on a personal and professional level, which has serious consequences for equitable and non-discriminatory provision of care to women and birthing people.

#### **Evidence**

Our call for evidence captured the voices not just of women and birthing people, but of those working within the maternity system, so we could understand how racism can impact on the workforce, examining how it affects healthcare professionals and their ability to give good care. More than two thirds (70%) of healthcare professionals who submitted written evidence identified as Black, Asian or Mixed ethnicity, a quarter (24%) as white and the majority were

midwives. Almost all of these responses stated that systemic racism and/or racial discrimination is contributing to maternity outcomes and experiences.

#### A toxic culture

"Fear of retribution does not encourage help seeking behaviours. But it does breed blame culture and a lack of accountability. Supported and resourced staff, coupled with a culture that encourages accountability is vital to the success of improving healthcare outcomes for patients." — Nova Reid

In the Morecambe Bay report, it was noted how the 'dysfunctional' culture within the maternity unit had impacted on staff and inevitably on the experience and outcomes for mothers and their babies. Similarly, the Ockenden report into maternal and neonatal deaths at Shrewsbury and Telford expose a culture where kindness and compassion from staff was missing. A culture of blame and bullying was referenced many times by the health care professionals we spoke to. Midwives who gave written evidence or contributed

<sup>&</sup>lt;sup>86</sup> Kirkup, B., 2015, The Report of the Morecambe Bay Investigation

<sup>&</sup>lt;sup>87</sup> Department of Health and Social Care, 2022, Final report of the Ockenden review

# 4. Findings and evidence Workforce representation and culture

to focus groups and interviews similarly referenced a 'toxic' culture within maternity services where staff treated each other with cruelty and unkindness –

"There were people trying to fit into a system that wasn't really respecting them. And so, the way that they felt they could find respect in that system, was to treat their own [i.e fellow staff] poorly."

The majority of midwives that participated in the inquiry reported feeling bullied by colleagues as well as disrespected and unsupported by the system. They felt that the mechanisms that were supposed to be in place to support them were instead used as tools to intimidate and threaten. Black midwives spoke of a mistrust towards the Nursing and Midwifery Council (NMC), whose own figures show disproportionate referrals of Black and other ethnic minority midwives and disproportionate sanctions against Black and Brown members who go through the Fitness to Practise process.88 Participants described how it was often referenced by management in a threatening and intimidating way, to elicit fear amongst staff.

"The NMC is being used as a bullying tool. How many midwives have been threatened having their PINs revoked, have been threatened to be reported to the NMC, they're used as a tool to bully, they're used as a tool to stop midwives from standing up and speaking out when they see something wrong."

Many midwives spoke of an atmosphere of fear and how it manifests to inhibit midwives and other staff from creating an environment where they are able to question and learn, which could lead to better outcomes for women and birthing people –

"There's a huge fear in the NHS of, if it went wrong it's going to be on your shoulders and it's your responsibility and litigation and a fear or losing your registration and I think all of these things are so on top of all NHS workers that there's an undercurrent that you practice in a fear based way, as opposed to the opposite which would be more probably conducive to having better outcomes."

Many spoke of the hierarchical structure of the NHS and how that has a detrimental effect on staff, entrenching a culture of bullying and affecting their ability to voice their concerns –

"I found it was a deeply hierarchical structure that had these weird layers within it of who's above who. That people coming in to give birth were at the bottom of the heap. But within the staffing, there were these layers and the bullying and the 'isms' across the board where there were, from top down, what I saw in practice was that somebody would be bullied and they would immediately, without even realising turn that around and whoever it was that they perceived as just below them in that pecking order, would be in the firing line. Almost like word for word repetition of the bullying."

#### **Experiences of racism**

Student midwives spoke of their exposure to racism when in clinical placements and the difficulties they faced when trying to challenge it –

"Yes, I'm still a student midwife. I'm in my second year now and I've experienced quite a lot of overtly racist comments in the short time I've been in my Trust. And I'm finding it really challenging because it seems to always be me who reports it and often it's, because I'm a student, I'm obviously the lowest of the low in the hierarchical structure."

Black, Brown and white midwives spoke about leaving, or wishing to leave NHS maternity care due to experiencing or witnessing racism. Some felt unable to speak up, while others who did escalate or whistle blow reported having to leave and facing harassment due to their actions.

"It makes me reluctant to continue in this profession where I feel completely othered and have to bear witness to abhorrent behaviours yet feel the power imbalance and consequences of speaking out make it difficult as a student."

Students spoke about not feeling supported by universities when they raised their concerns around racist behaviours and attitudes witnessed in the workplace, feeling they weren't taken seriously. They also reported feeling unsafe in clinical placements as they were subject to racist treatment from midwives, including those that were meant to be training them, and even after having reported the racist behaviour were made to continue working with those members of staff.

"I think the institutions that have students in placements, the educational institutions are failing our students across the board because they're going back to the universities and saying there's a problem. And the staff at the institution [...] are not using their protected position to fight the corner for students when students are reporting harm and sexism and racism, they are not using that position. [There is] something wrong with the relationship between education and practice [...] the education side of things, isn't supporting our students enough."

<sup>&</sup>lt;sup>88</sup> Nursing and Midwifery Council, 2017, Research on BME representation in Fitness to Practise process

# 4. Findings and evidence Workforce representation and culture

#### Representation and the "white ceiling"

In 2014, the report on the 'Snowy White peaks of the NHS' shone a spotlight on the lack of representation of Black, Brown and Mixed ethnicity people in leadership and governance roles within the NHS.<sup>89</sup> It is widely acknowledged that increased diversity within the NHS at all levels is essential<sup>90</sup> but an NHS England survey in 2017 found that Black and Brown people were underrepresented at Board level at just 7.7%, compared to 17.7% of the workforce.<sup>91</sup> In 2021, the NHS Confederation found Boards had become even less diverse.<sup>92</sup>

Healthcare professionals described to us the lack of representation in the workforce and explained that it affected them in several ways. Many reported that they didn't feel safe reporting racism to white managers and the lack of Black and Brown staff at this level meant they felt they could not voice their concerns as they would not understand. Some respondents to the written call for evidence described being accused of "playing the race card", being over-sensitive or imagining things.

"There's a particular [white] midwife [who] other [Black and Brown] midwives tell me they feel very kind of nervous around, they feel like they can't always ask for help as openly. That they feel they get more rolls with her eyes if they ask for any help as if they're really incompetent."

Others reported feeling let down or frustrated by senior management failing to act. The lack of robust, impartial, mechanisms to report racism left staff feeling vulnerable and wanting an alternative –

"I also feel that yes, the NMC needs to be taken apart and something needs to be put for midwives, by midwives because we don't have a voice, and this is being used as a tool against us when we raise our voice. I think these two things are deeply important and to recognise that quite possibly there needs to be a special, maybe, I don't know, part of the union, part of the Royal College of Midwives, that deals with and looks into and supports Black and Brown midwives."

Many reported the difficulties they faced trying to get into senior positions within their own workplaces, often feeling overlooked and having to work harder than their white counterparts to get recognition – described as a "white ceiling". Examples we received included Black and Brown colleagues being less likely to be promoted, facing harsher disciplinary sanctions, and Black student midwives failing more placements than white students. They also spoke of the impact of having a lack of role models and having no one who looks like or represents them in those positions –

"It's been really hard for me to get anywhere near where I feel like I want to be. And I look around me and in my own Trust, there is nobody [with] a coloured face within any senior position."

The evidence we received aligned with presentations by RCOG and RCM in the oral evidence session about differential attainment and discriminatory discipline for minority ethnic doctors and midwives.

#### Respectful care

Many respondents to our call to evidence described receiving more respectful and personalised care from Black, Brown or minority ethnic staff. Professionals also described Black and Brown women only feeling comfortable to raise concerns with ethnic minority staff.

"There was one doctor who was very good. She was an Asian doctor and she helped me to understand in my language and said, 'These are the negatives and positives.'"

"I just felt more at ease literally as soon as I knew the obstetrician was another Black woman."

"The only time I've had any kind of just kindness really or any kind of attempt to understand my situation or have a conversation with me was from the midwife from a marginalised group."

Another woman requested a Black midwife for the delivery of her baby and was told that she was not allowed to ask for this and that it was a 'racist' request, which she was distressed to find later had been recorded in this way in her maternity notes.

<sup>&</sup>lt;sup>89</sup> Kline, R. 2014, The "snowy white peaks" of the NHS: a survey of discrimination in governance and leadership and the potential impact on patient care in London and England

 $<sup>^{90}\,</sup>$  NHS Confederation, 2021, Strengthening NHS board diversity

 $<sup>^{91}\,</sup>$  NHS England, 2017, Supporting NHS providers to improve diversity in their Boards

<sup>92</sup> NHS Confederation, 2021, Strengthening NHS board diversity

# 4. Findings and evidence Good practice

# "Respect, bodily autonomy and just being heard."

- Participant, Leeds MVP Focus group

### **Finding**

Positive accounts of maternity care focused on good communication, person-centred and culturally sensitive care. This emphasises the critical importance of upholding the principles of respectful individualised care and dialogue enshrined in the Montgomery judgement and human rights law.

#### **Evidence**

Throughout the course of evidence-gathering, we heard from women and birthing people who described positive experiences of maternity care and who gave examples of excellent, culturally sensitive, person-centred care. Around one in ten written testimonies reported good care throughout their maternity journey.

Birthrights is aware of practitioners and institutions that have been working with Black, Brown and Mixed ethnicity women and birthing people in a supportive and inclusive way. Even within the accounts that told of poor experiences and breaches of human rights, many women were still able to give examples of good care and name at least one health care professional who was "amazing".

In the Survation poll, most Black, Asian and Minority ethnic respondents in the sample described positive experiences. 52% strongly agreed and 32% somewhat agreed they were treated with respect by doctors and midwives. 50% strongly agreed and 37% somewhat agreed that they were spoken to in a kind and friendly way.



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# 4. Findings and evidence Good practice

#### **Good communication**

Being able to communicate with the staff providing care for you, and feeling in turn that care providers are making every effort to communicate with you effectively, is one of the foundations of good care. Women repeatedly cited good communication as important in their experience. Listening to women and families was an essential action from the Ockenden report<sup>93</sup> and ensuring that the systems are in place to support a culture where individuals are heard is crucial to promote both improved experiences and safety.

"My experience was brilliant; it was really good... the midwife explained everything clearly and she made me feel at ease, to the point that I wasn't scared to give birth... Even the interpreters, they were brilliant."

"Every time, I was provided with an interpreter, and I had a very good experience from my midwife."

Good communication often took the form of ensuring appropriate translation services were accessible, but it was also described as an "open and honest" dialogue with midwives about an individual's preferences, including what risks and benefits related to different choices. One participant described her experience after discussing her choice to have a homebirth –

"They were just incredible and listened [...] they just kept me safe but at the same time really respected what I needed."

"I was really supported, everything was okay, I feel like I was listened to..."

#### Kindness and compassion

Being shown kindness was referenced by numerous women and highlights the simplicity of many women's needs. Words such as respect, kindness and compassion, which underpin the basic human right to dignity, were common and emphasise how important it is to focus on these core values to ensure a positive experience for Black, Brown and Mixed ethnicity women and birthing people.

"They were helping me, holding my hand, they were very soft, they were very considerate".

"Too much love and care...treated me like a queen; good staff, good people; they were good to me at the hospital..."

#### Personalised, culturally safe care

A midwife's response to call for evidence summed up what good care looks like:

"It means listening to people in our care. Respecting their choices as theirs to make. Always giving evidence instead of just assuming Western ideas are the best and other choices are inferior. It means having a diverse staff body so that the culture changes from within too. [...] It means proper training and real consequences for racist behaviours. It means being able to report our colleagues without fear. It means treating people like they are actually human, not just a skin colour or a name we haven't heard before. It means practising someone's name and getting it right and not stopping until we can say it. It means asking people about their cultural practices."

Some women described their cultural or religious preferences being respected, such as a Muslim woman who did not wish to see a male doctor, a nurse who facilitated a Sikh post-birth ceremony, and support to access halal meals or information about circumcision clinics.

Others described person-centred care, such as women with a history of miscarriage being given excellent aftercare and then consultant-led care for next pregnancy. Another participant told us about having a "thorough" consultant, who ensured she had extra appointments due to her pre-existing health issues. One couple who were supported to have a "relaxed, undisturbed" birth in the pool at home then experienced a "kind and respectful" conversation about needing to be transferred to hospital for a third degree care.

We also heard about examples of good practice initiatives including:

- Albany Midwifery Practice cited in the NHS Long Term plan as evidence for targeted continuity of carer. Published analysis demonstrated positive outcomes for women and babies in socially disadvantaged and Black, Asian, minority ethnic groups, including those with complex pregnancies and perceived risk factors.
- Bolton maternity hub in partnership with the Council of Mosques – located in an area with a high pregnant population and high percentage of Black and Brown residents. The hub brings care closer to home with an antenatal clinic, drop-in sessions, support in multiple languages, and will have family support and health visiting in future.

<sup>93</sup> Department of Health and Social Care, 2022, Final report of the Ockenden review



# 4. Findings and evidence Good practice

### Case study:

# a whole-organisation approach to anti-discriminatory practice

We received this case study in response to our request for good practice examples from organisations working in maternity care.

NCT supports parents from pregnancy to birth and beyond through interactive educational courses, one-to-one support, and evidence-based information. NCT trains and develops highly skilled practitioners to provide this parent support and information. The training programme for NCT practitioners is delivered in partnership with the University of Worcester, which won the 2020 Times Higher Education award for their "sustained, whole institutional approach to Equality, Diversity and Inclusion". The partnership provides education pathways with a strong focus on accessibility, inclusion, and anti-discriminatory practice.

NCT is committed to equity, diversity, and inclusion across their work and in 2020 brap were appointed as an independent inclusion advisor and learning partner. NCT's Chief Executive, Angela McConville, said: "The partnership with brap is a catalyst for reflection, learning, collaboration and change."

brap is a charity transforming the way organisations think and do equality; supporting organisations, communities, and cities with meaningful approaches to learning, change, research, and engagement. Joy Warmington, Chief Executive, brap told us: "Inclusion has become a word that everyone talks about, but few are able to realise and articulate in their work. NCT has seen an opportunity to fill this 'gap' – to understand more about how focusing on inclusion can help the charity deliver world-class support to all parents, supported by world-class staff, trustees, practitioners, and volunteers."

This work with brap extended to NCT's education model. Their new education programme launched in 2021 emphasises inclusion, diversity, and cultural competency, to ensure NCT students develop strong skills in the reflective, inclusive, and anti-discriminatory approach required to meet the needs of all parent groups, across all communities. This is done through an emphasis on reflective practice, informed decision making, exploration of systemic and personal biases, analysis of issues and the use of research-based evidence.

In collaboration with brap, NCT adjusted language and emphasis throughout the programme documentation and co-developed an anti-discriminatory practice unit for all NCT students as part of their core training. Companion training for course tutors and practitioner mentors working with students was also introduced to ensure a cohesive, connected approach.

Next, NCT and the University of Worcester will conduct research to explore the experiences of NCT students from Black, Asian and minority ethnic backgrounds, and their sense of belonging, connection, and self-efficacy within the community of NCT practice. This will help to: evaluate to what extent the anti-discriminatory practice unit is helping affect change; inform both future planning and delivery of training, and ongoing strategic work on diversity and inclusion; and "be part of the solution working towards an anti-racist future" (brap).

5.
Calls to action

#### 3. Calls to action

Based on the evidence gathered through the inquiry and analysis of the legal context, together with our expert panel we have identified five universal calls to action to achieve racial equity in maternity care.

We call on all parts of the maternity system to:

- Commit to be an anti-racist organisation
- Decolonise maternity curriculums and guidance
- Make Black and Brown women and birthing people decision-makers in their care and the wider maternity system
- Create safe, inclusive workforce cultures
- Dismantle structural barriers to racial equity through national policy change

We outline on the following pages concrete steps to achieve these goals. Birthrights commits to apply these to our own organisation and work with partners to identify their own action plans.

#### Calls to action

#### 1. Commit to be an anti-racist organisation

- Robust mandatory training on anti-racism and cultural safety for all staff, run at least annually
- Clear standards on what constitutes racism and discrimination in the workplace and service provision
- A clear pathway for reporting that ensures the safety of the person experiencing racism and encourages learning
- Foster a feedback culture that does not blame the person experiencing racism and delivers a timely, proportionate response to the perpetrator that encourages accountability
- Follow up on all reports of racism, ensuring some form of resolution has been achieved or action has been taken within a specific time frame to avoid unnecessary prolonged harm (4 weeks)
- Organisation-wide racial equity action plan, with named people accountable for delivery at every level and annual tracking to monitor the impact of training and other actions on both workforce and care provision [metrics could include staff wellbeing and retention, improved outcomes and fewer complaints]

#### 2. Decolonise maternity curriculums and guidance

- Robust mandatory anti-racism training for all educators, run at least annually
- Embed anti-racism and cultural safety as explicit principles within codes of practice and guidelines
- Wholesale review of education, examinations, training and clinical guidance to ensure the white body is not centred as the norm and that variations within specific ethnic groups are understood and addressed, without pathologizing Black and Brown bodies
- Recruit more diverse and inclusive representatives for guideline groups, advisory committees and lay-examiners using positive action in the Equality Act – set and monitor specific targets
- Ensure assessments address scenarios such as the impact of racial stereotyping and microaggressions, cultural awareness and the ability to give individualised care for all women and birthing people

#### Legal basis

Article 14 HRA – equity Equality Act – public sector duty

Article 2 HRA – safety Article 14 HRA – equity Equality Act – positive action

### 3. Calls to action

#### Calls to action

- 3. Make Black and Brown women and birthing people decision-makers in their care and the wider system
- Put Black and Brown women and birthing people in control of their care and respect their dignity, choices and concerns
- Implement tested, proven interventions and mechanisms that aid communication between minority groups and care providers, initiate regular check-ins and gather frequent feedback, especially for those at risk of racial discrimination or where harm has been caused, to re-build trust in communities facing disproportionate health outcomes
- Deliver existing Better Births commitments e.g. continuity of carer if appropriate, choice and personalised care, the right to change caregiver
- Invest in meaningful co-production throughout policymaking, led by Black and Brown people and with a well-supported pipeline and equitable processes for involvement
- Set targets for inclusive participation e.g. in Maternity Voices Partnerships to reflect local communities
- Accountability mechanism with community representatives, Maternity Voices Partnerships and volunteer peer links to track effectiveness of co-production and impact on quality of care

#### Legal basis

Montgomery – informed decision-making Article 3 HRA – dignity Article 8 HRA – choice

#### Calls to action

#### 4. Create safe, inclusive workforce cultures

- Build a culture of care, wellbeing, support and mentorship so Black and Brown leaders can thrive
- Set specific targets and use positive action to achieve increased representation of Black and Brown staff, especially within senior leadership
- All institutions to establish trauma-informed teams of 'Link Lecturers' for Black and Brown students who are responsible for their wellbeing and safety whilst at university and in clinical placements
- Mandatory training on trauma-informed practice and ongoing therapeutic supervision for all frontline staff
- Address toxic organisational culture and HR practices which allow bullying and racism to thrive unchecked, with named paid roles external to maternity units to promote and protect emotional wellbeing for staff
- National incentives set by NHS England and its counterparts for Trusts and Health Boards to track and positively address stress-related sickness
- Positive workforce culture initiatives and staff satisfaction within NHS Trusts and Health Boards to be measured by the Care Quality Commission and its counterparts

## 5. Dismantle structural barriers to racial equity through national policy change

- End NHS charging for maternity care
- Ring-fenced investment in NHS interpreting services with clear targets for local delivery
- Political commitment and target to end the ethnicity gap in maternal deaths – to achieve no difference in the rates of death for Black, Asian, Mixed and white ethnic groups by 2030
- Review the Maternity Incentive Scheme (CNST) to routinely capture ethnicity data at booking and address ethnic inequalities in maternity outcomes as core safety actions
- Revise the Birthrate Plus tool to include ethnic and social need data in calculations for staffing need e.g. to allow for potential extra time due to language barriers and cultural and social needs

### Legal basis

Equality Act – direct and indirect discrimination

Article 2 HRA
Article 3 HRA +
Montgomery –
informed-decision
making
Article 2 and 14 HRA
Equality Act – direct and
indirect discrimination



### **Appendix: Methodology**

#### Terms of reference

The expert panel agreed the scope and terms of reference of the inquiry at the outset.

Our agreed starting point was that systemic racism exists – in the UK and in public services. We wanted to understand how it manifests within maternity care and drive action to end it.

The inquiry aimed to shine a spotlight on:

- what racism looks like for people from different ethnic backgrounds
- the harm that it causes, both experiences and outcomes
- which fundamental human rights are in jeopardy
- the concrete solutions and actions needed to protect rights and end discrimination

The inquiry's scope was to focus on:

- Black, Brown and Mixed Ethnicity women and birthing people
- During maternity care: pregnancy, childbirth and up to six weeks post-birth
- The full range of outcomes and experiences faced by child-bearing people
- Concrete actions and solutions, including existing good practice

Our hypothesis was: systemic racism in the UK violates Black, Brown and Mixed Ethnicity people's basic rights to safe, respectful maternity care. Our lines of inquiry were:

- What does racism and bias look like in maternity care in the UK?
- How does it manifest differently for specific ethnic groups?
- What impact does racism and bias have on birth outcomes?
- What impact does racism and bias have on maternity care experiences?
- What harms are being caused to Black, Brown and Mixed Ethnicity birthing people?
- Which specific human rights are under threat?
- How does intersectional discrimination exacerbate outcomes and experiences?
- What does good look like concrete examples of anti-racist, culturally safe and rights-respecting care?
- What change is needed legal, policy, systemic, practice, individual?

#### Methodology

As a primary goal of the inquiry was to understand the stories behind the statistics, we adopted a qualitative methodology which included an online call for evidence, focus groups and in-depth interviews. Questions and scripts were shaped and agreed with the expert panel, to ensure they were inclusive, would elicit relevant information, and were not leading.

The online call for evidence for women and birthing people ran from March to August 2021 and was designed to reach a broad audience in an accessible way. It was hosted on Survey Monkey and translated into 16 languages. It consisted of 10 largely open-ended questions to capture people's experiences during pregnancy, birth and postnatally, and their perceptions of whether race and religion impacted on their care. We designed the questions to allow participants to tell the story of their maternity care in their own words, whilst giving some structure to support consistent analysis and identification of themes.

We created a shorter online form to secure written testimony from healthcare professionals, which was only available in English. The questions were similarly open-ended and focussed on whether healthcare professionals believed systemic racism exists within maternity services and if so, how this impacts on care provision and the workforce. We also sought examples of good practice, to identify solutions and to inform our final recommendations.

Both parts of the call for evidence were promoted widely online by Birthrights, community organisations, partners and healthcare stakeholders. We held 10 focus groups in partnership with community organisations, including:

- The Happy Baby Community (London five focus groups)
- The Raham Project (East Anglia)
- The Swansea Women's Asylum seeker and Refugee Group (Wales)
- The African Community Centre (Wales)
- The Latin American and Iberian Association (Wales)
- Leeds NHS Trust Maternity Voices Partnership (Leeds)

Due to the pandemic, the majority were held online via Zoom, but two were held face-to-face in a local community centre.

The structure and scripts for the focus groups were designed to be reflective and trauma-informed, to keep participants safe. Birthrights commissioned a therapist, Ese-Roghene Agambi, who specialises in working with women who have suffered trauma, to co-design the approach and offer optional debriefing support to both participants and facilitators. Safeguarding the emotional safety and wellbeing of participants was paramount, given the subject matter of the inquiry, which posed a risk of re-traumatisation. The structure and scripts were based on the post-traumatic growth model, which aims to empower people to tell their stories in a safe environment through 'strength-based', reflective discussion.

### **Appendix: Methodology**

All of the focus groups were co-facilitated by advocates from within the community. to ensure there was a familiar, trusted person present who spoke the same language and could put discussions in a cultural context which may be missing with only an interpreter. With Happy Baby Community, Birthrights trained former service users as peer facilitators, delivering a 3-hour skills workshop and supporting them to co-facilitate focus groups. This gave women with lived experience the opportunity to co-lead research and gain new skills, which was another way to 'reclaim their story' and take something positive out of difficult experiences - in line with the posttraumatic growth model of empowerment through story-telling.

We received positive feedback from participants that taking part in the focus groups was 'healing', supported peer learning and support, and helped them feel less alone.

We also held one online focus group for healthcare professionals – all attendees were midwives – which followed a similar semi-structured format.

We held in-depth interviews with participants who wanted to provide more detail about their experiences. Birthrights commissioned midwife and health activist Adelaide Harris of Black Beetle Health to conduct interviews with LGBTQ+ birthing people of colour, to explore the intersection between gender, sexuality and race. All interviews adopted the same traumainformed approach, with a strong emphasis on emotional safety and wellbeing.

We also interviewed clinical negligence solicitors and barristers to understand their perceptions of the role of racism in cases where women or babies experienced serious injury or death.

With support from panel members with expertise in qualitative methods and leading inquiries, we undertook a two-stage analysis to identify, test and confirm the main themes.

To supplement the qualitative evidence, we commissioned a poll by Survation which was conducted from 18-28 March 2022, targeting women aged 16+ who had children aged 5 and under living in the UK. The sample size was 556 white respondents and 513 Black, Asian and Mixed ethnic respondents. The poll aimed to test the main inquiry themes and compare the experiences of Black and Brown women with white women.

We delivered all evidence-gathering in line with Birthrights' policies on data protection and safeguarding, to uphold informed consent, anonymity and safety.

#### Limitations

This inquiry was not designed to be a formal academic study, although we have drawn on both research and community participation methods. It was important to adopt an approach that facilitated gathering the individual stories which are often missing from large-scale surveys or confidential reviews like the MBRRACE reports. We also sought to blend lived experience, maternity knowledge and human rights legal expertise from the outset.

Nevertheless, we are aware of limitations to our methodology. With a small-scale qualitative approach, we are unable to control for other factors that can influence worse outcomes and experiences in maternity care, such as pre-existing conditions or social determinants of health. Our starting point that systemic racism exists and explicit questions to test this hypothesis could generate confirmation bias. The design could also reflect our subjective perspective as Birthrights and individuals with our own lived and professional experiences.

As the sample was self-selecting, it is likely that we were more likely to hear from people with poor experiences and outcomes, including racism. We sought to mitigate this by framing questions neutrally, including explicit questions about positive experiences, and conducting the wider poll of over 1,000 women, including a 'control group' of white women.

For the online call for evidence, we did not collect other demographics such as gender, sexual orientation or whether someone had a disability, which limited the scope to explore intersectional discrimination. There were no responses in other languages despite the translated versions and the online format required access to a computer or smartphone and a sufficient level of computer literacy. This means the design excluded the voices of the most marginalised people with lived experience, although we mitigated this to some extent by targeting focus groups with specific communities. Though we sought to deliver a UK-wide call for evidence, there were limited responses from Scotland and Northern Ireland.

Notwithstanding these limitations, we believe the findings bring the voices of Black, Brown and Mixed ethnicity women and birthing people to the fore in a way that other research does not. As such, the inquiry is a powerful contribution to the discussion on how to urgently improve racial equity within maternity care.

