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Empowering Communities

Building Trust in Healthcare and Clinical Research



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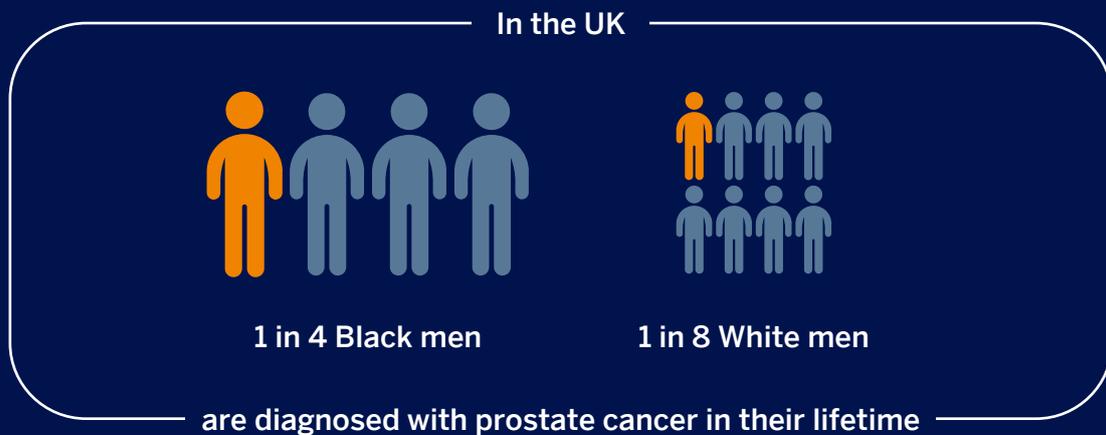


Executive Summary

The following report presents findings from the evidence generation and initial co-creation phase of 'Empowering Communities'; a project led by Prostate Cancer Research (PCR), with the research sponsored by AstraZeneca. The project explored how Black communities in the UK experience trust and distrust in health and research systems. The research used a mixed-methods approach, including a literature review, a national poll of over 1,000 Black British adults, community workshops and expert interviews.

While the desk-based research and literature review provided the historical, structural, and policy context for understanding how trust has been shaped over time, the polling quantified current patterns of trust and care experience. Through expert interviews, we gathered an understanding of how institutions interpret and respond to those patterns, and the community workshops revealed the lived realities beneath them. Together, these four strands of evidence create a comprehensive picture of how trust is built, eroded, and sustained, highlighting both points of convergence and areas of divergence across experience, perception, and system practice.

Key Context



Ethnic health disparities are also noted in maternal and psychiatric health (MBRRACE- UK, 2025; GOV UK, 2024). Additionally, Black populations are often underrepresented in clinical research (Pardhan et al., 2025). Trust has been identified as a critical factor in shaping how Black (and marginalised) communities engage with health services and research. Influenced by lived experiences structural inequalities and historical context, building trust requires a commitment to meaningful collaboration.



Findings

The study reveals a complex but consistent picture of trust in health and research systems among Black communities in the UK.

Living with systemic inequities:

Across the study, participants described health inequities as cumulative, relational, and deeply intertwined with broader social disadvantage. While many recounted positive and respectful care, others experienced dismissal, delayed diagnosis, and inconsistent treatment, eroding trust over time.

Polling showed that although 95% of respondents felt respected by healthcare staff and 89% felt listened to, nearly one in three had avoided seeking care after a negative experience. This illustrates the fragility of trust.

Expert interviews connected these patterns to “weathering” the cumulative impact of racism and chronic stress on health outcomes and warned that structural inequities, not individual attitudes alone, sustain these disparities. Workshops brought these dynamics to life, with participants linking poor care to inequities in housing, employment, and education. Representation among healthcare professionals was valued, but all sources agreed that equitable treatment and consistent competence mattered more than shared identity.

Together, the evidence suggests that Black communities’ trust in healthcare is shaped by a mixture of affirming personal encounters and enduring systemic inequities that must be addressed simultaneously to sustain confidence and engagement.

Trust and distrust in institutions:

Trust in health systems was found to be conditional and context-dependent. Polling showed high interpersonal trust (90% confident in clinicians) but weaker institutional trust, with 82% linking distrust to legacies of slavery, colonialism, and Windrush. Experts warned against US-centric models, highlighting UK-specific histories and inequities. Workshops revealed trust fluctuates by service type, continuity of care, and provider behaviour and participants often trusted individuals but doubted systems. Across all evidence, trust was seen as a reasoned judgment of fairness, honesty, and care quality, not an absence of doubt. This underscores that systemic transparency and continuity are critical to rebuilding it.



Findings

Representation and cultural responsiveness

Greater representation amongst healthcare professionals was broadly linked to greater comfort and trust, yet all sources agreed it was insufficient without cultural responsiveness and accountability. Polling found:



81% felt more at ease when staff understood their culture



79% supported more diverse representation in their medical team

Workshop participants valued representation but prioritised empathy, adaptability, and communication that reflected cultural norms. Experts stressed that symbolic inclusion without structural change risks tokenism and called for self-scrutiny, co-production, and sustained investment in equity.

The concept of reciprocity was present in the workshops, as it was felt that Black communities were often asked to provide data, time and experiences, without adequate acknowledgement. This can undermine trust and reinforce historical patterns of exploitation. The sharing of information, including results, outcomes and feedback to enable co-ownership was key to the acknowledgement of communities as partners and a recognition of their contributions. Together, findings suggest that trust grows not from visibility alone but from authentic, responsive partnerships that share power and learning; shared values and behaviours matter as much as shared identity.

The power of communication

Clear, culturally relevant communication emerged as the strongest determinant of trust. Polling showed personal and family experiences shaped attitudes more than official sources, with 47% citing stories from relatives and 44% social media.

Workshops revealed that intergenerational storytelling deeply influences perceptions of healthcare, and communities favour trusted local messengers such as faith leaders or barbers over celebrity figures. Experts highlighted the success of community-led models in vaccine uptake, showing culturally attuned communication drives engagement. Participants wanted both detailed information and simple summaries. Across all evidence, effective communication was relational – listening and co-creating messages builds trust, while generic or inconsistent communication erode it.



Recommendations

To strengthen trust between Black communities and health and research systems, the report offers several key interconnected recommendations:

1. Strengthening community partnerships for sustainability and research

Work with trusted community-based organisations to build long-term capacity, sustainability, and resilience in health engagement. This partnership model would provide funding, training, and leadership development, enabling these groups to maintain year-round activity and stable roles within local health ecosystems. It would also support co-produced, community-led research activity, using participatory methods to improve research literacy and trust.

Through PCR's patient data platform, Prostate Progress, partners could access insights on community needs and outcomes, helping align programmes, share learning, and secure local investment. This collaborative infrastructure would reduce dependency on short-term projects, create paid community roles, and foster continuity of trust between institutions and the people they serve.

2. Trust building clinics and drop-in sessions

Build Community Trust Hubs with partners such as Can-Survive UK, CAHN, Black Thrive and 100 Black Men of London. Based in trusted venues like churches, mosques, barbershops, and community centres, each hub would offer culturally rooted spaces for health advice, social connection, and research participation.

Hubs could host drop-ins with clinicians and patient advocates providing guidance on navigating the NHS; from GP registration and referrals to screening and clinical trials. Alongside, cultural and food

events such as "Taste & Talk" evenings or storytelling dinners would make health dialogue engaging and relevant.

Participants could contribute anonymised experiences through PCR's patient registry, Prostate Progress, receiving feedback on how their input drives change. Grounded in the findings, the hubs link lived experience, cultural identity, and system knowledge helping move healthcare from a distant institution into a community partnership built on trust and understanding.



Recommendations

3. Cultural responsiveness training and engagement

Advocate for establishment of mandatory, ongoing cultural responsiveness programmes for healthcare and research professionals. Training should combine historical context, reflexive practice, communication skills, and co-production methods with community

input. Embedding it within professional development ensures consistent delivery. This directly responds to the communities' calls for empathy, adaptability, and awareness of systemic inequalities, moving beyond tokenistic representation to authentic cultural engagement.

4. Amplify local voices in health messaging

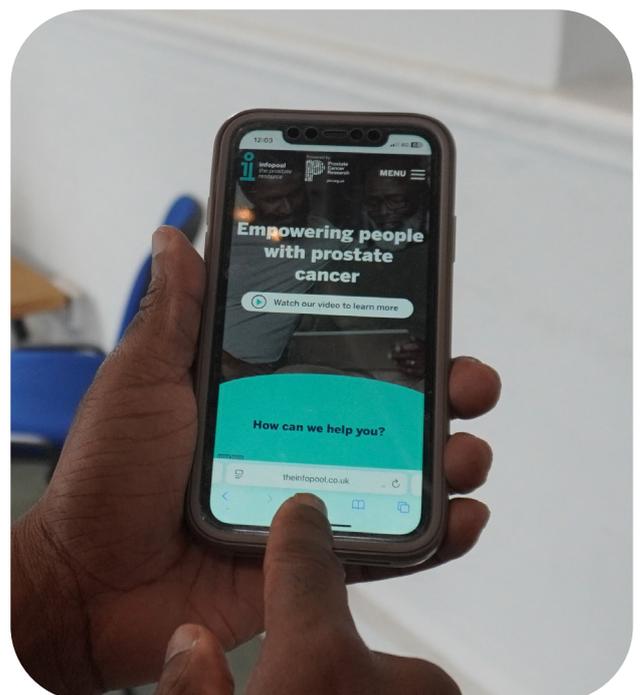
Develop and test health messages with communities, not just for them. Materials should reflect local language, values, and preferences, and be delivered through trusted community figures. By incorporating storytelling and multiple

levels of information depth, this approach builds understanding and credibility while countering misinformation. It reflects community feedback that effective communication is a dialogue grounded in respect and choice.

5. Trust and accountability reporting

Develop a public "Trust and Equity Index" tracking institutional progress on engagement, representation, communication quality, and responsiveness.

Data and reports should be shared and disseminated annually to promote transparency and system-wide accountability. This builds on expert calls for measurable, sustained change and signals to communities that trust is being earned and monitored, not assumed.





1. Introduction

Background and rationale

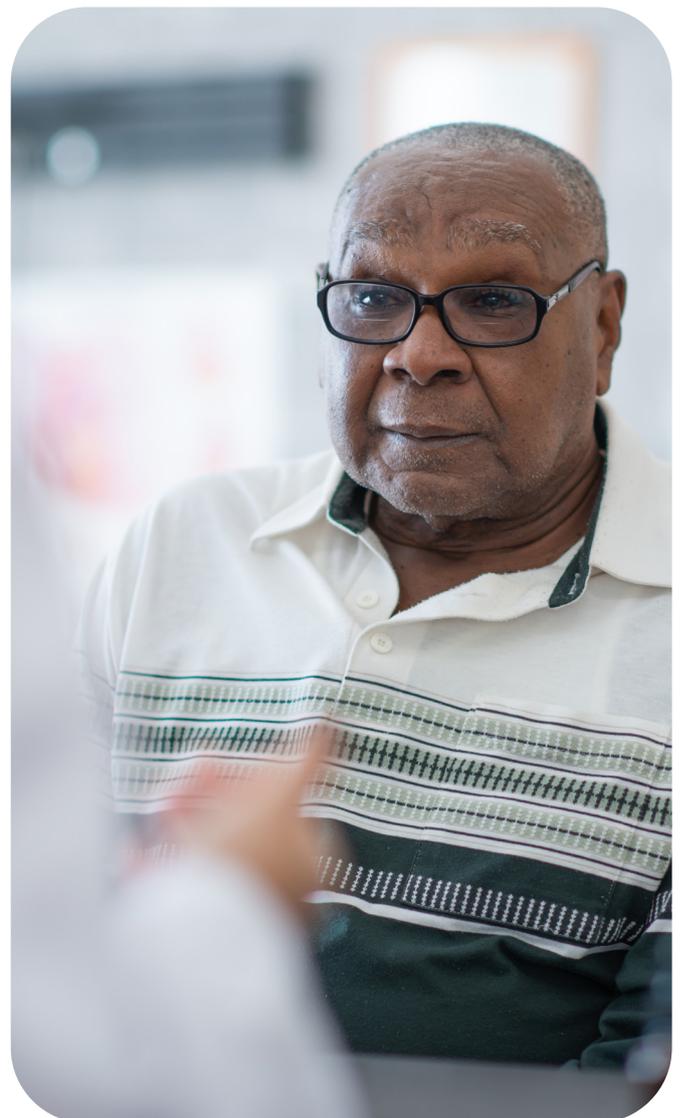
Trust in healthcare systems and research is fundamental to achieving equitable health outcomes. Within Black British communities, trust in health institutions and research is known to be influenced by a combination of factors including personal experiences, historical contexts and wider social and structural inequalities.

In the UK, Black men are disproportionately impacted by prostate cancer, with 1 in 4 men expected to be diagnosed in their lifetime. This compares with 1 in 8 White men and 1 in 13 Asian men. Data from the National Prostate Cancer Audit highlighted that Black men have higher rates of stage III and IV (more advanced) prostate cancer than any other ethnic group in England (BMJ, 2025; National Prostate Cancer Audit, 2025).

Empowering Communities, led by Prostate Cancer Research and sponsored by AstraZeneca, was created to build a deeper understanding of trust amongst Black communities of healthcare and clinical research. We have done this by centering the perspectives of specific Black communities and recognising them as collaborative partners. By engaging directly with Black British communities to understand experiences of healthcare and clinical research, we aimed to deepen and share understanding of the specific barriers which limit equitable participation and engagement.

Drawing upon a mixed-methods approach, this report integrates multiple sources of evidence to explore trust. The research includes community workshops, expert interviews, a literature review and national polling. By utilising both qualitative and quantitative evidence, the project supports the design and implementation of building culturally responsive strategies for healthcare and research.

Crucially, Empowering Communities has sought to amplify the experiences and priorities of Black British communities. In creating opportunities for dialogue and reflection, this project aims to strengthen the capacity for communities to shape health and research systems. The findings contribute to broader health equity strategies and offer insights into collaborative practices. This work also builds a foundation to co-create opportunities for meaningful engagement and to develop solutions to build trust.





1. Introduction

Objectives

The key objectives of this report include:



Trust and distrust

An analysis of the historical and contemporary factors influencing trust and distrust in health services amongst Black British populations.



Gather data

To gather and synthesise data from literature, polling, expert interviews and community workshops.



Recommendations

To develop practical recommendations to support the co-creation of trust-building strategies across health research, services and policy.



Research participation

To contribute to a wider evidence base for equitable health and research participation.

These objectives demonstrate a commitment to strengthening health and research systems for equitable care.



2. Methodology

A mixed-methods approach was utilised to explore trust and relevant barriers in Black British communities. Four complementary strands of evidence were collated between April to August 2025, these being:

Literature review

To establish historical and structural context and available evidence base.

Polling survey

To generate representative, quantitative insights.

Expert Interviews

To capture perspectives across academia, clinical medicine and community leadership.

Community workshops

To explore lived experience and co-create solutions for change.

Each strand provided a distinct contribution to build a more comprehensive understanding of trust. The literature review consolidated existing evidence and identified critical gaps. National polling provided quantitative evidence of contemporary attitudes and behaviours within Black British communities. The community workshops expanded the analysis to include qualitative data and a deeper exploration of lived experience. Expert interviews provided additional insights into institutional perspectives. Together, these evidence strands allowed for the identification and contextualisation of common themes and challenges in building trust.





2. Methodology

2.1 Literature Review

A structured literature review explored existing literature regarding healthcare and clinical research trust amongst Black British communities, with a particular focus into historical, social and cultural dimensions.

The review utilised a thematic process, reviewing existing scholarship across 5 key domains:

1

Historical context

2

Structural and systemic barriers

3

Cultural & community specific beliefs

4

Distrust in research and clinical trials

5

Improving practices and community-led solutions

Sources included peer reviewed journals, NHS and governmental reports, grey literature, ethnography and historical documents.

A systematic approach was utilised to search relevant databases including PubMed, JSTOR and Taylor and Francis online.

The inclusion criteria:

- Literature focusing on Black communities in the UK (or with a clear relevance to Black British populations and their diasporic origins, from continental Africa and/or Caribbean).
- Literature published in English, extending from 1947 to 2025.

The exclusion criteria:

- Studies/research focused on non-UK populations without any applicable insights relevant to Black British communities.
- Literature not published in English.



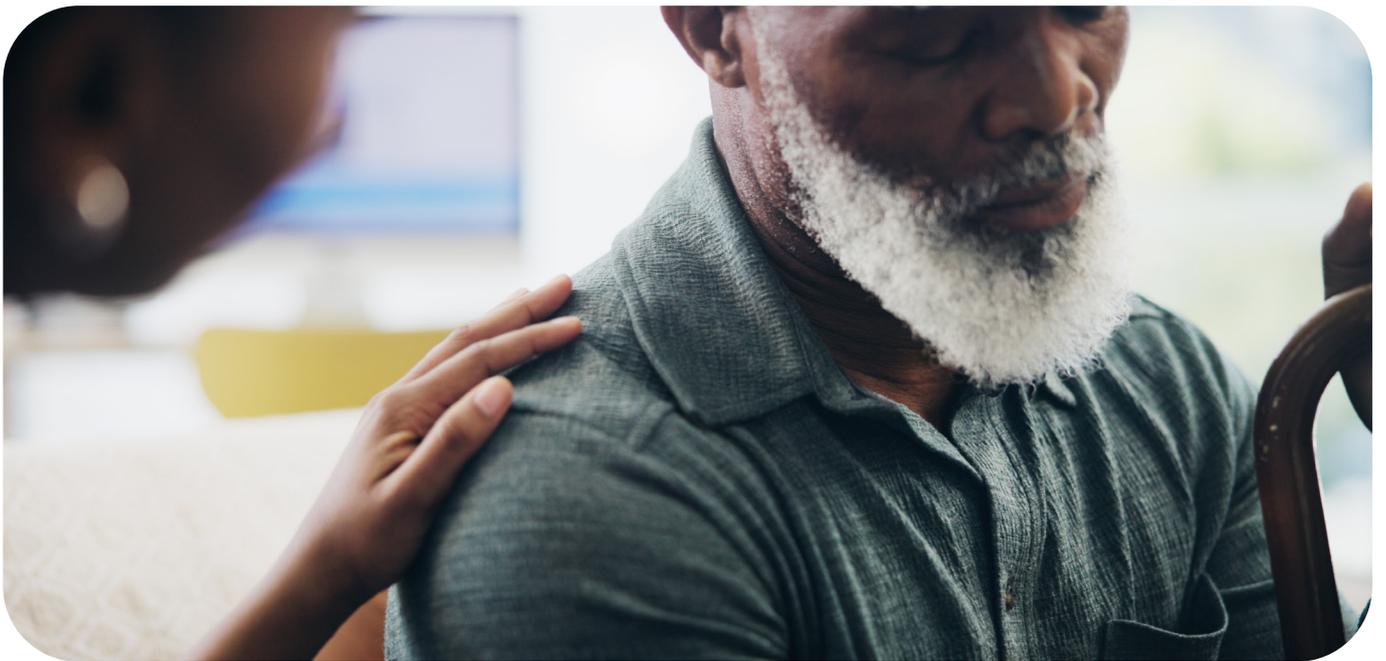
2. Methodology

2.2 Polling Survey

A survey of 1,050 Black British adults was conducted to provide insights into trust and barriers to trust. The survey captured attitudes, beliefs and experiences relating to health services, research and trust. The survey was distributed across three regions of the UK: London, North-West England and the West Midlands, with 350 respondents selected from each region. Respondents identified as Black, Black British, Black African, Black African Caribbean, or of mixed Black heritage. The polling was delivered by OnePoll, July 2025.

The survey explored trust and barriers to trust, whilst also examining healthcare experiences, health communications and the influence of historical events. This included the trans-Atlantic slave trade, colonialism, and the Windrush legacy.

Questions included Likert-type rating scales, multiple choice items and open text responses, allowing for both qualitative and quantitative insights.



2.3 Expert Interviews

Semi-structured interviews were conducted with individuals across clinical medicine, academia and community leadership.

Interviews, lasting 30-45 minutes, were conducted remotely. Informed consent was given by participants.

Key areas of focus were guided by a topic framework. Topics discussed included perceptions of trust and distrust, historical and social contexts and inclusivity in research.



2. Methodology

2.4 Community Workshops

Participatory workshops were convened with Black British communities in London, Manchester and Birmingham. Sessions were designed to be accessible, culturally responsive, and inclusive. In total, 53 individuals participated, with diversity in age, gender, migration background, and health experiences. Community groups, charities, local authorities, faith and local networks supported recruitment.

Workshops were structured as 3-hour sessions and facilitated by Prostate Cancer

Research. Each session incorporated plenary discussions, small breakout groups and open forum segments. Additional logistical and administrative support was provided by staff from Prostate Cancer Research. Representatives from AstraZeneca also attended in an observational role.

Participants provided informed consent to take part in the workshops with anonymised notes recorded by staff members and reimbursement for their time and contributions.

Focus areas included:

- Personal experience with healthcare systems and health research
- Broken trust and distrust
- Moments of care and moments of harm
- Visions and strategies for improved trust and health equity

The workshops were fundamental in generating grounded insights. These events provided a space in which to explore rich perspectives and authentic experiences, in a safe environment.





2. Methodology

2.5 Strengths and Limitations

This study was designed to capture a multi-dimensional understanding of trust in health and research systems among Black British communities. Using a mixed-methodology approach, the research sought to capture both breadth and depth. While the study offers valuable insights, both strengths and limitations should be acknowledged.

A key strength of the research is the focus on trust within a UK context, which addresses a significant gap in contemporary research. The use of both qualitative and quantitative methods allowed for greater breadth and depth of insight. Additionally, the involvement of a multitude of community perspectives created space for nuanced discussion.

However, we acknowledge the limitations. The poll reached 1,050 Black British and Black mixed-race adults and 53 individuals participated in the community workshops. According to the 2021 Census, the Black population in England

and Wales was approximately 2.4 million (Office for National Statistics, 2022). The population of individuals with a Black mixed heritage was approximately 760,000. It should be noted that the Census only provides data for specific mixed groups (White/Black Caribbean and White/Black African). Other individuals with Black mixed identities are not separately identified and may be included in the broader 'Mixed Other' category.

The polling and workshop figures are not fully representative of the diversity of perspectives amongst Black British populations. Digital access barriers may have excluded individuals without reliable internet access to survey participation. Additionally, recruitment for the workshops relied on online sign-ups, which may have been a barrier to some individuals. Despite this, the findings reflect recurring themes across all data sources and offer salient insights for practice and policy.





3. Findings

3.1 Experiences of health and social inequalities

Experiences of health and social inequalities were described across the study as complex, cumulative and relational; a common thread running through all of these findings is the concept of weathering. This is understood as the cumulative impact of chronic stress, discriminatory practices and structural inequalities on the health of Black (and marginalised) communities.

Perceptions of inconsistency and inequity were among the most common barriers discussed by workshop participants. While individual clinicians or researchers were often trusted, participants highlighted that the quality of care varied considerably. This was often determined by geographic region, attitudes and behaviours of health professionals and perceptions of clinical competency.

Though positive accounts of respectful and high-quality care were reported, others described experiences of exclusion, poor communication and delayed diagnoses.

Survey findings suggested that most respondents experienced positive interpersonal interactions when seeking care. 95% of respondents who accessed care stated they were treated with respect, 89% felt listened to and 86% reported being included in decisions. However, nearly one-third (31%) reported that they had avoided seeking care because of a previous negative experience.

While many workshop participants reported positive experiences on an individual basis with healthcare professionals, these were often outweighed by social inequalities, broader structural issues, and experience of systemic racism. The influence of intersecting structural disadvantages, such as inequalities in housing, employment, and education, on poor health outcomes was flagged by many workshop participants. This was mirrored by the findings

of the literature review, which also highlighted the relationship between health inequalities and social determinants of health.

“Trust is when they understand you as a whole – your condition, your culture, your job. You always know if they care, or if it’s just a job.”
– Workshop participant

In another example of weathering, unconscious bias and institutional neglect were also identified as key contributors to inequalities across health and research, leading to individuals having to bear poorer health outcomes and negative clinical experiences. This phenomenon was felt to be critical to understanding distrust and research hesitancy amongst Black communities.

Several participants also reported unsatisfactory treatment and care from Black and minority ethnic health professionals, underscoring that while representation is valued, it is not a guarantee of trust. Participants described their disappointment when encountering bias, dismissiveness or hostility from professionals of a similar ethnic background, and emphasised respectful, equitable treatment and clinical competence as the foundation of trust. This further suggests the idea that trust depends less on shared identity and more on shared values and behaviours.



3. Findings

3.2 Trust and engagement with health institutions and research

Trust was recognised throughout the study as a critical determinant of healthcare engagement and research participation. Much of the existing scholarship is drawn from US contexts, in which historical cases of research exploitation are frequently cited as key contributors to distrust.

Two of the most cited cases are the Tuskegee Syphilis Study and Henrietta Lacks. In the former, the US Public Health Service conducted an experiment on the effects of untreated syphilis in Black men between 1932 to 1972. Infected men were falsely informed that they were having treatment for “bad blood” and denied access to effective treatment (Reverby, 2001).

Henrietta Lacks was a Black American woman diagnosed with cervical cancer. Following unsuccessful treatment, her cells were shared with researchers without her consent or knowledge. While her cells generated vast scientific and commercial value, Lacks’ family did not receive any financial benefit.

Expert interviewees emphasised that trust in healthcare is influenced by the interactions of global, local and personal histories and experiences. Additionally, clinicians, researchers and institutions should have an awareness of these histories, if seeking meaningful engagement. However, the resonance that these high-profile US examples have for Black British communities is unclear, and expert interviews cautioned against an overreliance on US frameworks of racialised distrust. They reported that smaller numbers of patients/service users did reference US cases, though these instances were limited.

Even so, both our polling data and insights shared in the community workshops relate trust with socio-historical context. More than half (53%) were aware of incidents in which Black communities were treated unfairly in healthcare. Additionally, 82% believed the historical legacies of slavery, colonialism and the Windrush scandal influence trust in the UK health system.

Community workshop discussions highlighted that trust could be undermined at both the personal and systemic level. Many participants recalled multiple experiences of affirming care whilst others recounted experiences of feeling dismissed. Across conversations, common areas emerged in which distrust was most acute, including maternal care, mental health and cancer services. This may reflect wider inequalities including disproportionate detention under the Mental Health Act and higher rates of maternal mortality (GOV UK, 2024; MBRRACE- UK, 2025).

Some workshop participants felt particularly neglected regarding continuity of care and aftercare. One individual described the lack of continuity as “falling off a cliff”. Others highlighted their enduring relationships with healthcare professionals, which provided support through challenging health issues.



3. Findings

3.2 Trust and engagement with health institutions and research

However, weakened trust between patients and healthcare professionals was understood by participants as both an individual and systemic issue. Many workshop participants agreed that increasing workloads, greater demand for services and short appointments limited the capacity of clinicians to build relationships with patients. This was reflected in our survey data, which shows that whilst the majority of respondents (90%) expressed confidence in healthcare professionals to deliver good care, trust in institutions and research was more conditional.

Researchers and research institutions were often viewed as more distant and obscure than healthcare providers. Concerns were raised about financial motivations of research, how findings would be used and whether researchers genuinely cared about outcomes for patients and their communities.

Some participants felt they did not have access to adequate information to understand the value, risks and benefits of clinical trials, and some were concerned around the timing of research requests. They felt that if an individual was invited to participate in research at a time they were particularly vulnerable, for example, during a cancer pathway, it might compromise their ability to give informed consent.

Despite these reservations, several individuals reported positive and empowering experiences of clinical trials. Many highlighted health improvements and a desire to add to knowledge that may benefit future generations. Several participants referred directly to their children and grandchildren, whom they hoped would benefit from their own contributions.

The polling survey suggested that awareness of clinical research was relatively high, but uneven.



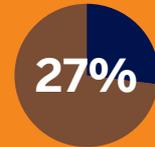
Could correctly identify a clinical trial



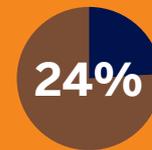
Reported feeling comfortable taking part



Were unfamiliar with the term



Wanted more information before deciding



Stated that they required full safety assurances

These figures suggest that the willingness to participate in clinical research exists, but engagement is strongly associated with clarity and transparency.



3. Findings

3.3 Representation and Cultural responsiveness

The importance of representation was a consistent theme. However, participants expressed nuanced ideas about the meaning and impact.

Existing literature highlights the importance of representation and cultural responsiveness in improving trust among Black communities, although representation is not a substitute for structural change across health policy, leadership and the delivery of care. There is recognition that traditional models of cultural competency, which focus upon acquiring knowledge about different groups, are insufficient.

Cultural responsiveness, a dynamic, reflexive approach which allows for more meaningful engagement with communities, is emerging as a substitute. Cultural responsiveness refers to the ability to engage effectively with people of different backgrounds, by adapting communication and practices to reflect their values, needs and experiences.

Polling results demonstrated that representation and cultural responsiveness was associated with trust in health systems and research. The majority of respondents (81%) who had received care (n=1,041) stated that they felt more at ease when staff understood their culture, with nearly half (48%) strongly agreeing.

Community workshop perspectives regarding racial and ethnic representation in health services and research were more varied. For some participants, Black representation amongst healthcare professionals and researchers offered reassurance and support and similarly, some participants stated they would be more willing to engage with research led or co-led by Black or minority ethnic investigators.

In the polling survey, 79% of respondents agreed that increasing representation would strengthen trust, with 44% strongly in agreement. This highlights that for many individuals; representative staffing is a key component of equitable and responsive care. However, others argued that representation alone was insufficient. The necessity for clinicians and researchers to demonstrate cultural responsiveness and a willingness to learn and adapt was strongly emphasised.

Expert interviews also highlighted that genuine engagement with Black communities requires more than symbolic inclusion. Representation of Black professionals was seen as helpful, but not a substitute for accompanying practices of institutional accountability.

Another central theme was the need for reciprocity across health and research practices. Many community workshop participants felt that Black communities were often asked to provide data, time and experiences, without adequate compensation or remuneration. This dynamic can undermine trust and reinforce historical patterns of exploitation. Reciprocity denotes the acknowledgement of communities as partners and a recognition of their contributions. Additionally, reciprocity requires the sharing of information including results, outcomes and feedback to enable co-ownership.

Several experts acknowledged the ongoing efforts of individuals, from a wide range of backgrounds, already engaged in equitable research. However, without sustained institutional investment, their impact is often limited. Many experts stressed that building long-term relationships is essential to strengthening trust.



3. Findings

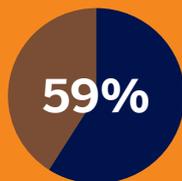
3.4 Communication, education and health messaging

Communication emerged as a critical factor in shaping trust in Black communities. The literature review highlighted the central role of communication in shaping public trust. Studies demonstrated that health messaging without relevance, clarity or representation may contribute to distrust. Research also acknowledged the importance of accessible, culturally affirming health communication as more likely to build understanding and participation.

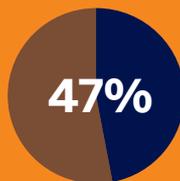
Within some Black communities, intergenerational experiences and familial storytelling often serve as significant sources of health knowledge. Younger community workshop participants reported fewer direct interactions with healthcare professionals and institutions. However, familial and social narratives strongly shaped their expectations of health services. Accounts of harmful practices (e.g. being ignored, delayed diagnoses, pain dismissal) or neglect passed down through generations were described as contributing to distrust. In contrast, positive examples of culturally responsive care reinforced participant trust.

Polling Results

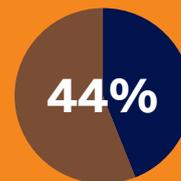
Polling results also identified the role of intergenerational narratives in shaping trust in the health system with the following key influences being identified:



Personal experiences



Stories from family and friends



Content from social media platforms

These findings emphasise the importance of both community, networks and digital channels in health trust.

The literature also discussed the importance of trusted messengers (including faith and community leaders) in bridging the gaps between communities and institutions.



3. Findings

3.4 Communication, education and health messaging

Expert interviews further reinforced the utility of trusted messengers as essential intermediaries between health systems and Black communities. These messengers were involved in organising and facilitating meetings, workshops and training activities. Experts noted that similar partnerships between churches and grassroots organisations were effective in increasing COVID-19 vaccine uptake in Black communities.

In contrast, some workshop participants were wary of health messaging or recruitment that relied on celebrity endorsements. Though such figures could attract significant attention, individuals not directly connected to community realities were regarded as lacking cultural resonance. Instead, participants advocated for the amplification of trusted local voices, with authentic understanding of local concerns.

Workshop participants also noted the importance of education and effective communication to build trust in health research. Many called for clear and accessible health information, to enable communities to understand health conditions, treatment pathways and navigation of the wider health system.

However, expectations varied considerably amongst individuals. Some participants strongly valued highly technical, detailed clinical explanations. This included the provision of drug formulae, testing protocols and statistical data. Other participants preferred more simplified messaging, with concise summaries. A common theme was the importance of offering choice in the depth of information provided.

“Some people need the full facts, risks, side effects, everything, before they can trust it. It’s not one size fits all. The doctor has to give you the choice and explain in properly.” – Workshop participant

Concerns regarding challenges in the communication of research studies/recruitment information, treatment options and clinical decisions were also discussed. Several workshop participants felt the clinicians and researchers lacked the ability to adequately articulate study designs, risks, benefits and potential outcomes in clear, culturally relevant manner. As such, this communication barrier contributed to distrust.

There was strong support for health messaging and education to integrate practical guidance on healthy living and understanding clinical research. Participants described holistic health education as a gateway to wider engagement and trust in healthcare.

Across all strands of evidence, listening to communities was highlighted as a fundamental priority. Many participants also emphasised the importance of increasing the diversity of perspectives from Black communities. Collaboration with a broader range of Black individuals extending across age, region, ethnic identity, gender, and sexuality was frequently encouraged.

Workshop participants and expert interviews also reported that the same individuals were frequently relied upon repeatedly to represent Black communities in health communication and engagement work. While these individuals had valuable insights, this approach was seen as unrepresentative and limiting. Participants stressed that many other organisations were doing effective work but remained unrecognised or under-resourced.



4. Discussion

Across the evidence, trust in the health system and research emerged as a deeply mixed picture. Many participants described powerful moments of positive, individual interactions with health and research professionals.

Polling data indicated



Nearly 9 in 10 respondents who had accessed and received care were confident that healthcare professionals provided good care

There were many similar encouraging findings that suggested many participants feel respected and listened to in clinical encounters.

There was a profoundly complex and often fragile layer of institutional distrust. Almost a third (31%) of survey respondents reported that they or someone close to them had avoided treatment due to a previous bad experience. Further accounts emerged throughout the workshops and interviews, of individuals being dismissed and unheard in clinical settings. Inconsistencies in care and treatment access were also described. This perceived lack of equity undermines broader trust in health systems and research.

Workshops and interviews also emphasised that trust is shaped by both lived and inherited experience. Many participants pointed to the role of family histories and intergenerational memory in influencing their perceptions of health systems, with younger participants drawing upon the experiences of their parents, grandparents and communities.

Findings also suggested that trust is highly conditional and contextual. It may fluctuate depending on the setting (i.e. primary versus secondary care), the service (i.e. mental health services versus cancer care) or the individual attitudes and behaviours of health professionals. For some, familiarity and continuity of care nurtured and built trust. For others, brief and inconsistent interactions with and poor communication from healthcare professionals and inaccessible treatment options erode trust. Consequently, trust should be understood as a dynamic process, which may fluctuate and evolve over time.

The evidence demonstrated that trust is not an abstract sentiment, but a measured judgement of whether care is equitable, respectful and competent. Participants stressed that perfection is not a realistic expectation. Rather, they require a willingness to show honesty, consistency and genuine partnership between clinicians, researchers, communities and individuals. When these conditions are met, trust is (and can be) strengthened substantially.

Overall, the evidence challenges characterisations of Black communities as 'hard to reach' or 'mistrustful'. Black British communities have expressed a strong willingness to engage, but also a deep awareness of systemic shortcomings and inequalities. Mistrust should not be viewed as an irrational phenomenon, but a reflection of the health system's functional ability to deliver health needs reliably.



4. Discussion

Barriers and Enablers to Trust

The evidence suggests that trust in health and research systems is continually shaped by daily interactions, structural conditions and institutional relationships with Black communities. Across the data, several consistent barriers and enablers to trust emerged.

Barriers to Trust

Perceptions of inconsistency and inequity were among the most common barriers discussed. While individual clinicians or researchers were often trusted, participants highlighted that the quality of care varied considerably. This was often determined by geographic region, attitudes and behaviours of health professionals and perceptions of clinical competency.

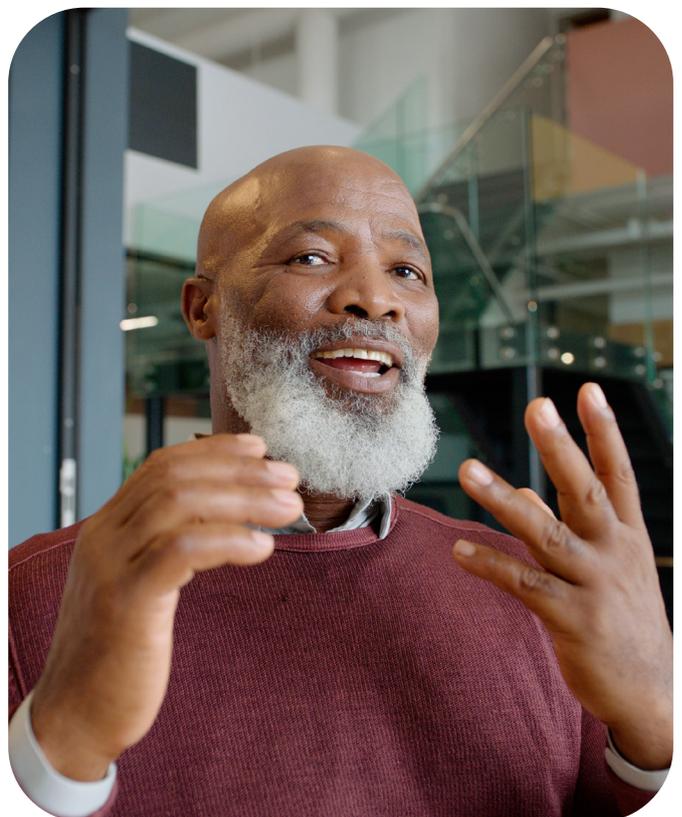
Another frequent concern was the erosion of relationships between individuals and clinicians, especially within primary care settings. Short consultation appointments and the lack of continuity of healthcare providers limited opportunities to build trust. This was especially important for patients managing long-term chronic conditions. Many participants highlighted the need for holistic treatment and a recognition of their cultural and family contexts.

Delays in diagnosis and unconscious bias also undermine trust. Participants highlighted being dismissed in early consultations, only to receive diagnoses at advanced stages. The literature further highlighted that distrust was often shaped by cumulative experiences, frequently emerging from sustained patterns of neglect or exclusion.

The history and legacies of systemic racism have formed a salient influence on trust. While few participants directly referenced cases such as the Tuskegee Syphilis Study and the Henrietta Lacks case, there was an emphasis to highlight UK histories and context, such as Windrush. Across the evidence, a recurring theme was the importance of institutions, researchers and clinicians, to engage meaningfully with Black

British and colonial histories and their impact on trust.

A further barrier was the perception of health communications and research as often being imposed upon communities rather than being done with them. While the polling data suggested relative openness to participation in clinical trials, many participants required more detailed explanations. In the absence of transparency and reciprocity, research within Black communities risks being perceived as extractive rather than collaborative.





4. Discussion

Enablers of Trust

This research has brought a range of challenges into clearer focus; but, crucially, our work also uncovered trust enablers and actionable solutions.

Of these, one of the most important is person-centred, empathetic care. Communities valued healthcare professionals who provided holistic care and open communication. It is important that healthcare professionals demonstrate their willingness to respect cultural norms, beliefs and communication styles.

Culturally responsive communication is a key enabler to trust. Language and messaging that reflects the diversity of Black British life – across different ages, gender, ethnicity, migration histories, language, sexuality and faith – resonates with communities.

Community members cite clear explanations, attentive listening, and the affirming of their lived experiences as important. Overall, education emerged as a mechanism of empowering Black communities, researchers and clinicians alike to build and strengthen trust.

It is vital that initiatives are carried out with communities and not done to them. Collaborative and community-led approaches (including co-production and design of research) can be credible and empowering with community, charity and grassroots initiatives acting as powerful advocates. However, these initiatives are far too often under-utilised and under-resourced.





5. Recommendations

The evidence presented in this report indicates that building trust in healthcare and clinical research amongst Black British communities requires structural and cultural change. Trust must be sought through sustainable actions, accountability and a willingness to transform institutional cultures and practices.

These recommendations are intended as a resource for charities, researchers, healthcare professionals, policymakers and institutions.

Recommendation 1: Strengthening community partnerships for sustainability and research

Working with trusted community-based organisations to build long-term capacity, sustainability, and resilience in health engagement would support co-produced, community-led research activity. However, many community groups are under-utilised due to lack of capacity and resources. Capacity building, so that these groups can maintain year-round, stable activity, would improve both the quality and relevance of clinical research in Black British communities, positioning Black communities to contribute and lead in research and knowledge production.

The programme should be structured around practical, community-led mechanisms that embed accountability, transparency and equity throughout.

Actions may include:

Strengthening Community Groups:

Funding, training, shared access and leadership development for community groups.

Community Health and Research

Ambassadors: Recruited from within communities, trained, resourced, and supported to act as liaisons between researchers, clinicians, and community members, translating relevant specialist information into accessible language and facilitating communication between researchers and communities.

Community review panels:

Establish independent panels of community representatives to enhance research accountability, through, for example, advising on study design, ethics, and alignment with community priorities and needs.

Community access to research findings:

Ensure outcomes are shared with participants and communities via co-designed materials, reviewed by panels or ambassadors, and delivered in accessible, culturally appropriate formats.

Co-production and participatory

methods: Build partnerships through the provision of research methodology training for community members, peer research training and support, co-design workshops, and shared decision-making in research processes.

Targeted research fellowships and grant opportunities:

Structured fellowships and grants programmes for Black researchers and those committed to advancing Black health equity in research. It may be useful to consider opportunities for ongoing support and resources for early, mid and senior career stages.



5. Recommendations

Recommendation 2: Trust-building clinics and Drop-in sessions

The establishment of trust-building clinics in trusted community venues could provide a viable mechanism to strengthen trust. Hosting informal, repeat sessions in trusted spaces creates opportunities for sustained engagement and trust building, beyond the clinical environment. Trusted spaces may include churches, mosques, barbershops and community centres. It is important to note that different communities may have different trusted spaces.

Potential formats may include:

- Joint facilitation by a local GP or nurse alongside a trusted community leader.
- Themed sessions on community-relevant topics such as patient rights, consent, research pathways, and navigating healthcare.
- Q&A opportunities to support an open, inclusive environment.
- Culturally safe environments and practices, including appropriate food, language and facilitation.
- Online options for remote communities.
- Limited researcher participation through listening, answering queries, and explaining how community input shapes their work. Recruitment activity should be precluded from these clinics.





5. Recommendations

Recommendation 3: Cultural responsiveness training and engagement

A structured, practice-orientated programme designed to strengthen researchers' and health professionals' knowledge, awareness and practical skills. Through ongoing training, professionals develop the capacity to recognise the influence of history, culture and identity on health and research experiences. This process can strengthen professionals in their ability to provide more equitable services and contribute to building trust with Black communities.

This programme could include:

Historical and structural context

Reinforce understanding of Black British and colonial histories, research inequities, and their impact on health trust.

Reflexivity

Building skills in self-reflection, recognising personal biases, and understanding positionality.

Inclusive communication

Training in active listening, recognising microaggressions and harmful practices in research. Practising plain language communication and working across different cultural health norms.

Prioritising lived experience in the co-production of new work

Developing organisation's knowledge, skills and mechanisms to prioritise lived experience and community integration into new models of work.

Continuing Professional Development (CPD)

Embedding training within CPD frameworks to sustain its practice.

Delivery model

Facilitated by organisations or equity experts with lived experience and practice-based knowledge using modular formats with interactive elements (e.g., role-play and guided reflection.)





5. Recommendations

Recommendation 4: Amplify local voices in health messaging

Effective health messaging and education has been highlighted as central to trust, whilst inconsistent and misaligned health messaging have contributed to distrust in Black British communities.

Possible solutions include:

Co-production in health messaging

Develop health and research messaging in partnership with communities, ensuring that they are relevant and reflect relevant nuances for specific communities. There may be scope for collaboration with other health organisations.

Expand community-based education

Co-produce and deliver health education in trusted community spaces, such as faith centres, barbershops, libraries, schools, with Black communities. Collaborative design with other organisations and stakeholders could address intersecting and persistent health disparities in Black communities across one or more health conditions.

Recommendation 5: Trust and accountability reporting

Develop a public “Trust and Equity Index” tracking institutional progress on engagement, representation, communication quality, and responsiveness. Data and reports should be shared and disseminated annually to promote transparency and system-wide accountability. This builds on expert calls for measurable, sustained change and signals to communities that trust is being earned and monitored, not assumed.



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Authors

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