WELLBEING OF WOMEN

The Health Collective: Grassroots Organisations' Views on **Women's Health**

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MHP Group

Foreword

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Wellbeing of Women has worked tirelessly for almost 60 years to save and change the lives of women, girls and babies. We are the only UK charity committed to improving women's gynaecological and reproductive health throughout their life course. A key part of our work involves addressing why women experience poorer health outcomes compared to men. Shockingly, the UK has the widest gender health gap in the G20 as our health system has been designed by men for men. Men have historically been treated as the default patient in both clinical practice and medical research. As a result, women's healthcare needs have been consistently ignored and neglected.[i]

The UK Government recognised this disparity with the launch of the Women's Health Strategy in July 2022, which promised to tackle the deeply rooted inequalities in our healthcare system to improve the health and wellbeing of women across the country.

Nowhere is this gender health gap more pronounced than for women from diverse ethnic groups. The 2022 National Institute for Health and Care Research (NIHR) study, which was part funded by Wellbeing of Women, found that women and their babies who are from Black or minority ethnic communities experience worse outcomes during pregnancy and the postnatal period.[ii] This is simply unacceptable and cannot be allowed to continue.

The Health Collective has emerged out of the urgent need to do more to ensure all girls and women receive the best care, regardless of their race and ethnicity. It is being led by grassroots organisations representing women's voices from every community in our society. The Health Collective aims to ensure that their voices are heard and used to influence Government policy via the Women's Health Strategy and create collaborative solutions to overcome many common challenges.

This initial report represents the output from The Health Collective's first meeting in September 2023 during which we discussed the key challenges experienced by the members of the Health Collective, and their suggestions for potential solutions we could introduce to overcome the barriers they have met.

First and foremost, the members talked about the lack of trust that their communities have in the NHS. Years of not being listened to and historical evidence of medical mistreatment have led to a loss of faith in our health systems and the people who run them. Rebuilding that trust is a vital step towards remedying the situation which can only be achieved by working closely with the grassroots organisations connected to these communities.

Members told us that health information is frequently inaccessible to them for many reasons and that this has led inevitably to lower health literacy among these women. They also suggested that many medical professionals would benefit from training in cultural sensitivity. Above all else they felt that community groups doing vital work to support these disadvantaged women within their communities lack sustainable funding.

We believe this report is the first step in the newly formed Health Collective's journey to empower grassroots organisations from diverse communities to achieve meaningful changes to improve the health of women and girl in their communities. The HC will continue to meet and make recommendations to those in power and connect communities so that they can share their experiences and work together to make a difference.

In the coming months The Health Collective will be expanding its membership to include grassroots organisations from other traditionally marginalised communities such as disabled, refugee and LGBTQ+ women.

One year on from the launch of the Women's Health Strategy, we recognise that diverse voices are needed to achieve our plans to improve healthcare and wellbeing that will truly benefit all women.

Background

In response to the growing recognition of the unique health needs and challenges faced by women in England, the Women's Health Strategy for England was developed and published in June 2022 to address longstanding gaps in women's healthcare and to promote better health outcomes for women across the country.[iii]

The Strategy was implemented to raise awareness of gender disparities in healthcare, the need to address issues such as reproductive health, mental health and violence towards women, and a commitment to promoting women's rights and equality. It was written following a call to various advocacy groups, healthcare professionals and women themselves, who highlighted the need for a comprehensive approach to women's health.

In response to this, Wellbeing of Women formed **The Health Collective**, a collaboration of grassroots Black, Asian and other ethnic minority groups that support women's health in their communities, with the aim to ensure their voices and knowledge are fed into the delivery of the Women's Health Strategy and help to address the stark health inequalities across society.

The objectives of The Health Collective are to;

- Support ongoing work that grassroots organisations are **already doing** to support their communities
- Ensure that **diverse women's voices are heard** and can influence Government policy via the Women's Health Strategy
- Create **collaborative solutions** between members to overcome many common challenges
- Identify barriers to equitable healthcare and suggest ways to overcome them. Promote types of care that women from marginalised communities **want in a way that works for them**

On 20 September 2023, Wellbeing of Women, convened the first event of The Health Collective, bringing together a diverse group of individuals and organisations who are passionate about improving women's health, especially for marginalised communities. The event aimed to highlight the work being done by grassroots organisations and identify barriers to and opportunities for improving women's health. MHP Health has supported The Health Collective with a summary of events that day and subsequent production of this report.

The event was attended by over 30 participants, including healthcare professionals, community advocates, researchers and charities. Many attendees shared their experiences as marginalised women navigating the healthcare system. For many, these experiences inspired them to create safe spaces and support services catering to underserved groups. The discussions highlighted a clear need for better engagement, culturally competent care, improved funding models and cross-sector collaboration. This report summarises the key themes and outlines recommendations to help drive action towards more inclusive women's health services.

The launch of the Health Collective was supported by the National Lottery Community Fund.

Key **recommendations**

Core themes arose from the discussion, which stemmed from the barriers women from marginalised groups face in accessing healthcare. From these insights, the following recommendations are proposed to support grassroots organisations in better serving women within communities.

Funding and resources

- Sustained core funding for women's health organisations, especially at community level
- Multilingual, accessible and culturally relevant health education resources
- Regional partnerships and platforms to unite advocates nationally
- Employer support for women's health work as a valued service

Grassroots community engagement

- Improved engagement and co-production with marginalised populations
- Spaces for women to speak openly about stigmatised health issues
- Support from men as allies in breaking society's stigma and taboos

Health system improvement

- Enhanced training for healthcare professionals on cultural competency and bias
- Better data collection and representation of the impact of treatments and interventions for diverse communities

What **barriers** are marginalised groups facing in accessing women's health services?

The first area for discussion by The Health Collective, highlighted how the COVID-19 pandemic had shone a light on the long-standing health disparities affecting ethnic minority communities. These groups often suffer from worse health outcomes, such as higher rates of chronic illnesses and mental health issues, as well as obstacles in accessing healthcare. The Health Collective identified several major barriers that marginalised groups face when seeking women's health services. Healthcare organisational structure, policies, and practices can unintentionally disadvantage these populations and perpetuate health inequalities.

Inadequate service provision is clearly demonstrated via maternal mortality statistics, which is high within ethnic minority groups across the UK. Recent research shows that the rate of women dying in the UK in 2018–20 during pregnancy or up to six weeks after the end of their pregnancy was 3.7 times higher within the Black community, and 1.7 times higher in the Asian group, compared with the White participants in the study.[iv] Deprivation and pre-existing medical problems are significant risk factors for maternal mortality.[iv]

Poor access to health and social care is commonly a result of barriers to the delivery of health services. Marginalised communities often face significant obstacles to receiving basic health and social care.[v] Marginalised communities include those who have been historically excluded from involvement, as well as those continuing to face other barriers to civic participation. This includes those marginalised by factors like race, wealth, immigration status, and sexual orientation.[vi]

Lack of adequate health information
and support tailored for marginalised communities

Today's complex healthcare systems require individuals to play an active role in managing their health. People are expected to find information, make decisions, communicate effectively, think critically, and solve problems related to their care. These skills comprise health literacy. Adequate health literacy enables people to navigate the system and make optimal choices. Nearly half of adults in Europe have low or marginal health literacy, especially marginalised groups[vii]. Studies show that higher health literacy links to greater self-efficacy, better self-management of chronic disease, adopting healthy behaviours, utilising preventive services, and lower costs. Poor understanding of health information is conversely associated with worse outcomes like higher mortality, poorer self-reported health, increased emergency care use, and more chronic illness[viii].

The Health Collective highlighted inaccessible information as a dominant barrier to access. Materials are often not culturally relevant or translated, relying on husbands or relatives to interpret medical information, which can be misrepresented due to bias and reduces the autonomy of the patient. Mainstream guidance rarely represents diversity in images and messaging. Not having community representation can create a negative perception of how patients view the healthcare system and their trust in healthcare professionals. The discussion noted frequent experiences from the women of knowledge gaps around stigmatised women's health topics due to taboos, preventing patients from seeking medical support. People from marginalised groups generally have inequitable access to healthcare due to a lack of accessibility, encountering poorer patient-professional communication and are significantly disadvantaged when service provision is not tailored to individuals' unique needs or preferences.[ix]

Language barriers and low health literacy heavily impede access to services. It was noted that materials for patients are rarely available in other languages or simpler to understand text. Illiteracy and cultural barriers prevent comprehension of health information, often causing women to be unaware of what medical assistance they require.

Healthcare professionals lacking **cultural competence and bias** training

In today's world, healthcare providers are tasked with treating a growing number of patients from diverse cultural and linguistic backgrounds. The significance of cultural competence is clear as it directly impacts the quality of healthcare.[x]

During the discussion, the women noted that healthcare providers regularly show unconscious bias when delivering care to diverse patients. The failure to understand cultural and religious nuances and hesitancy suggests that clinical pathways have been designed through a white-centric lens - this is an area which should be reviewed in collaboration with marginalised communities.

Culture-related communication problems have been identified in research, including cultural differences in explanatory models of health and illness, differences in cultural values, cultural differences in patients' preferences for doctor–patient relationships, racism and perceptual biases, and linguistic barriers.[xi] Studies have found that physicians are often poorly cognisant of how their communication patterns should vary with respect to the characteristics and background of the individual they are treating.[xii]

A study examining nurses' views on cultural competence training in Finland found sessions increasing self-awareness were considered highly valuable. Training that builds understanding of one's own cultural traits and biases may improve communication between providers and patients, a key aspect of quality care. The findings suggest cultural competence training should be more widely accessible to larger groups of healthcare professionals. Future opportunities could leverage e-learning platforms to allow participation anytime, anywhere.[x]

Funding limitations for community organisations supporting women's health

Women's health community organisations are key in improving health access and empowerment work for marginalised communities. However, these groups face monumental challenges in securing the funding required to sustain and grow their impact.

The Health Collective discussed grassroots organisations' current reliance on short-term grants versus core funding to sustain work, limiting the scope of impact and provision they can provide. For most organisations, the main income sources are short-term government and trust grants that come with tight restrictions on allowable activities. This project-based funding model leaves little room for core operating costs like staff and overhead that provide the backbone for organisations to thrive. Groups supporting the most marginalised women struggle greatly to access any funding at all.

The Health Collective additionally referenced that grassroots groups are often overlooked for major funding opportunities, despite having a critical role in the delivery of service provision and support within the community. Well-intentioned criteria often inadvertently exclude smaller organisations. Groups lack the time, skills and extra hands for fundraising amidst delivering frontline services. Collaborations like consortium bids allow pooling resources to access larger pots, yet multi-year unrestricted funding is truly needed for stability.

There is a pressing need for funders to engage more with women's groups to grasp their realities and build funding models that nurture rather than starve community organisations. Only then can funders become true enablers of the women's empowerment work urgently needed to create a more equitable health system.

On an individual level, the lack of financial compensation for patient advocates sharing lived experiences was noted. For the patient's voice to be recognised, lived experience is crucial to understanding the gaps in care and the situation within each locality. Resource constraints on time and capacity of women's health advocates are worsened by a lack of workplace support.

Improving the capacity of grassroots organisations will be key in the implementation of the Women's Health Strategy, otherwise, the funding barrier will halt any progress made during this period.

Exclusion of marginalised communities in research, media and policy conversations

- Service structures and policies are not always conducive towards providing equitable care. Organisational structures, policies and practices are often tailored towards the needs of the majority, with less consideration for those in the minority, and who remain excluded.
- Leadership roles concentrated among the majority.
- Patient voices from diverse groups left out of shaping policy and service delivery.
- A problem for policymakers is that there remains little evidence to support interventions for groups, who are under-represented in research.
- There is an under-representation of people medically under-served in empirical evidence, particularly for participation in randomised controlled trials.[xiii]
- Social media algorithms also discriminate against marginalised groups.

Additional barriers discussed by the group also included **difficulty building trust and engagement with marginalised groups.** Many marginalised communities have negative prior experiences with the health system. Those experiences often influence future interactions.

Historical exclusion and current marginalisation have bred mistrust. Mainstream services fail to effectively reach diverse audiences, partly due to gatekeepers controlling access in close-knit communities. Women can be prevented from seeking health and social care support.

Additionally, insufficient data collection on health outcomes and experiences of diverse populations results in growing evidence gaps in critical areas such as maternal mortality. This leads to policies and interventions based on incomplete information that overlooks inequities.

There is a **need for more regional/national collaboration and less territorialism** as territorial mindsets pit groups against each other in the race for limited resources. London-centric activity patterns further concentrate opportunities geographically. By building networks enabling partners across regions and issues to share knowledge, amplify impact and harmonise advocacy, the women's health movement can transcend divides to advance together.

The group also discussed the need to open up the Health Collective to other marginalised groups such as disabled, refugee, LGBTQ+ and economically deprived women.

Highlighting some of the **key activities** already happening **locally** to support marginalised women's health

As part of the second area discussed by The Health Collective, participants represented diverse roles and organisations supporting women's health locally. Many run impactful community programmes and events targeting the needs of marginalised women. However, most operate in siloes without widespread visibility. There is a tremendous opportunity for synergies by linking advocates across geographies and health focuses through shared platforms, funding and events.

- Breast cancer support groups and helplines for South Asian women
- Workshops on sexual health in places of worship to reach different communities
- Providing menstrual products to tackle period poverty
- Training caregivers on compassion fatigue prevention
- Podcasts and social media tailored for minority audiences
- Advocacy and support groups for conditions like endometriosis, fibroids and adenomyosis
- Research on biases in clinical pathways and maternal health outcomes
- Events providing menopause education for Black women
- Helping minority women transition back to work after health challenges
- Ongoing community outreach on stigmatised women's health topics
- Language services and culturally tailored health education
- Building partnerships with local providers to improve care
- Capacity building for minority nurses, midwives and other HCPs
- Coaching on nutrition, mental health, chronic conditions, and wellbeing
- Interfaith forums bringing women together across cultures
- Campaigns highlighting inequalities and lobbying for policy change
- Support for domestic violence survivors from various backgrounds

How can **grassroots organisations** access support

Along with the NHS' long-term plan, the Health and Care Bill promoted integration and partnership working to improve health and tackle health inequalities. With action led by integrated care systems (ICSs) and integrated care partnerships, place-based partnerships to work alongside people and communities are critical to improving social care provision and addressing the needs of the local system. [xiv] There is a role for local governments to support health outcomes. Working with health and wellbeing boards, ICS partnerships and local economic partnerships can enable whole-system action on health inequalities.[xiv]

To scale impact, expand reach, and better serve women locally, participants expressed interest in the following types of support:

Funding support

Adequate resourcing is seminal for community organisations to achieve sustainable impact. Unrestricted multi-year grants enable strategic planning and capacity building requisite for organisational durability. Core operating support should be augmented by targeted capacity building investments to strengthen internal infrastructure.

Enhancing access necessitates dedicating funding especially for grassroots and marginalised groups contending with systemic resource deprivation. Intermediary organisations can facilitate connections with institutional power structures. Support with proposal development, evaluation, and fiscal sponsorship nurtures grassroots grantee success.[xv]

Equitable research and advocacy require financially compensating community members for their time, experience, and emotional labour. This formalises lived experience as expertise and surfaces community priorities.

Grassroots community engagement

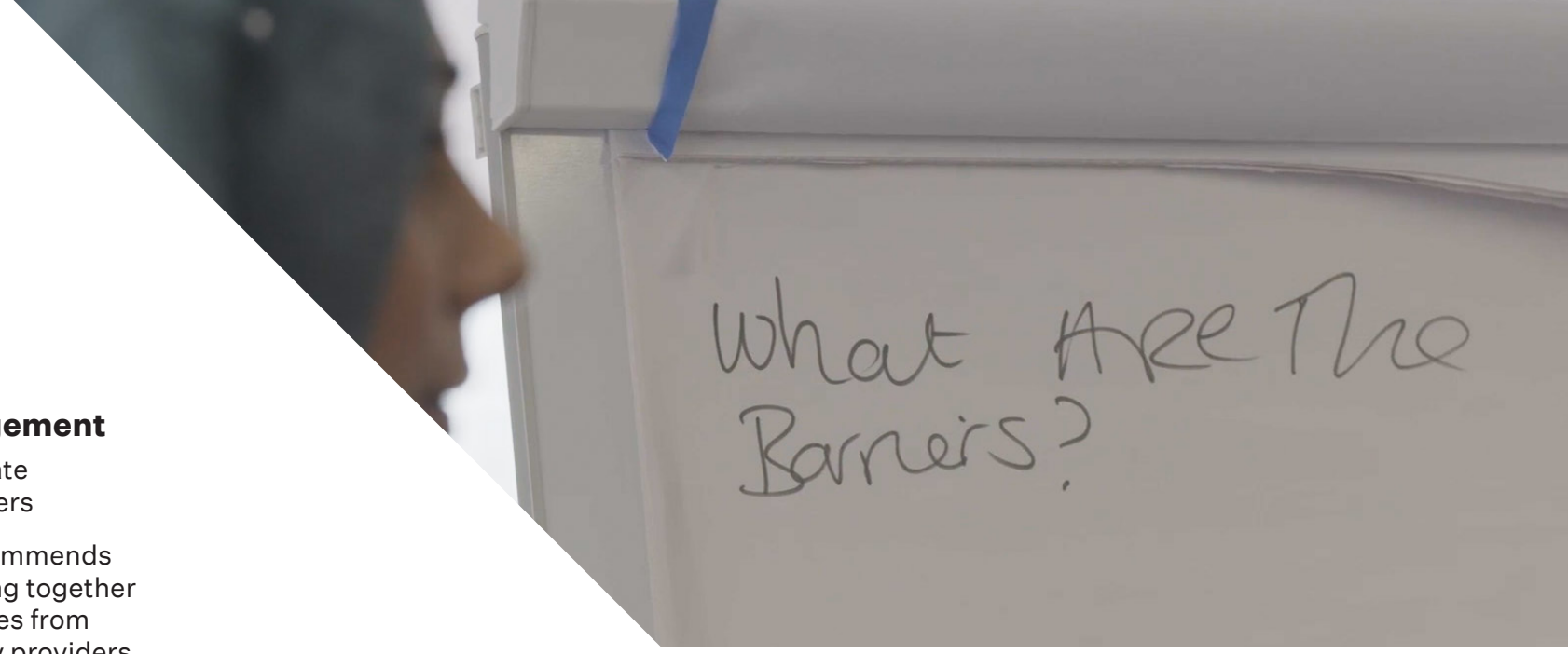
Expanding the ability to reach diverse communities necessitates strategic partnerships with trusted community institutions possessing the relationships. As part of NHS England's Core20Plus5 initiative to support the reduction of health inequalities, trust must be built with people and communities by communicating in a way that allows people to understand and use information to make decisions about their own health and ultimately respect their choice.[xvi]

Culturally tailored education materials and lived experience representation foster relatability. However, surface-level cultural sensitivity without examining systemic biases risks perpetuating microaggressions.[xvii]

Sustainable progress requires investing in cultural competence across clinical and organisational dimensions. Evidence-based interventions encompass diversifying leadership and staff, immersive bias training centred on self-reflection, interpreter services, and participatory development of policies and materials.

While cultural knowledge aids contextualisation, patient-centred care equally values understanding individual needs and barriers. A multifaceted cultural competency approach addressing explicit and implicit bias at structural and interpersonal levels is imperative for dismantling entrenched health disparities.

- Programmes to recruit and retain diverse staff members; cultural competency training for healthcare providers; use of interpreter services to ensure individuals from different backgrounds can effectively communicate; culturally appropriate health education materials to inform staff of different cultural backgrounds; and provision of culturally specific healthcare settings are key interventions to improve cultural competence.[xviii]
- Healthcare disparities can be reduced through a patient-centred approach to cultural competency training, general knowledge of the cultural context of clinicians' patient population, and attention to the effects of racial bias and discrimination among both clinicians and non-clinical staff.[xviii]



Healthcare System Engagement

- Tapping networks to disseminate education through local providers
- Health Education England recommends the use of Training Hubs to bring together education and training resources from NHS organisations, community providers as well as local authorities. There are 42 at Integrated Care System (ICS) level, with several locality hubs that help support links between practices and Primary Care Networks (PNCs). Training Hubs are usually run by a clinical leader and a manager supported by a network of primary care staff with education and training professionals based in the community[xix]
- Advocating for improved services and cultural competency training
- Placement of community health workers in clinical settings
- Messaging should reinstate that everyone is welcome in general practice and, if necessary, challenging system and professional barriers within health services to ensure people access the services they need[xx]
- Cultural competency emphasises the need for health care systems and providers to be aware of, and responsive to, patients' cultural perspectives and backgrounds. Both patient centeredness and cultural competence are needed in striving to improve health care quality[xi]
- Healthcare providers must openly reflect on and discuss issues of the patient's culture, including ethnicity and race, gender, age, class, education, religion, sexual orientation and identification, and physical ability, along with the unequal distribution of power and the existence of social inequities, to effectively co-construct a treatment plan that is patient centred and culturally sensitive[xi,xviii]

Policy Engagement

Achieving health equity necessitates centring communities impacted by structural marginalisation within policymaking processes. This requires resourcing advocacy capacity building and participatory mechanisms for meaningful patient engagement.

While technical expertise is valued, lived experience constitutes equally vital policymaking expertise. Patient voice representation disrupts traditional power dynamics by formally integrating community insights into decision-making forums.

Summary

By coming together under the umbrella of a collaborative network, participants felt marginalised women's health groups could jointly access capacity-building resources, gain visibility, share learnings, and harmonise advocacy efforts for greater impact.

Political ownership for implementing the Women's Health Strategy is vitally important. Its delivery will require motivated and enlightened ministerial leadership, following the 2024 election. It will be up to researchers, clinicians, and the public to hold our government to account, citing their ambitions back to them and ensuring women in England are indeed heard.

In summary, the event highlighted major gaps in meeting the needs of marginalised women but also showcased the passion and potential for change through cross-sector collaboration. Implementing the recommendations in this report can help create more inclusive clinical pathways and close disparities in women's health outcomes.

Appendix

The Health Collective

The Health Collective is a group of grassroots Black, Asian and other ethnic minority groups that support women's health in their communities with the aim to ensure their voices and knowledge are fed into the delivery of the Women's Health Strategy and help to address the stark health inequalities across society. The group agreed that a shared platforms to showcase their work nationally and the linkages with other advocates working on aligned issues will improve best practice sharing and allow them to increase their bargaining power. The group will meet quarterly and a directory of their work will be housed on the Wellbeing of Women website.

The Health Collective is made up of representatives from the organisations below as well as other individual advocates.

Wellbeing of Women

Led by women's voices, Wellbeing of Women's mission is to improve gynaecological and reproductive health and wellbeing through research, education and advocacy. We want a future where every single woman has access to high-quality and accurate healthcare and information. We exist for all women with representation that is inclusive and diverse, with women informing our areas of impact.

MHP Health Advocacy

MHP Health's mission is to enhance and extend people's lives by building campaigns which change the way that patients, professionals, and policy makers think and act. We combine expertise in government affairs, health systems policy, patient advocacy, PR and digital activation to help our clients' campaigns deliver tangible outcomes. Our clients, whether global pharmaceutical companies, Patient Advocacy Groups or small providers, work with us because we help them look around corners and navigate an ever-changing, complex environment.

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