

NOTHING ABOUT US WITHOUT US

Lothian Pilot



What Exactly Is this Initiative?

Nothing About Us Without Us is a community participatory initiative which aims to end inequities in maternal health outcomes and experience for womxn of African descent (WAD) living in the Scottish diaspora through asset-framed, culturally nuanced, empowering community education, participation and accountable co-production.

In November 2023, we are piloting this initiative in Lothian for WAD living across East, West and Midlothian. This initiative is a collaboration between the Edinburgh-based organisation [KWISA \(Women of African Descent in Scotland\)](#), communities of WAD and the [maternity voices partnership \(MVP\)](#) in NHS Lothian.

This collaboration aims to reclaim the narrative around the reproductive well-being and aspirations of people from the African diaspora living in Lothian. The African diaspora consists of descendants of involuntary and voluntary emigration out of Africa, regardless of their place of birth or nationality. Therefore, we acknowledge that WAD may also be nationals of countries in the Caribbean, North America, South America, Central America, Europe, Asia, Oceania, and Africa.

This initiative is focused on the primary users of maternity services who are individuals assigned female at birth who may identify as women, non-binary folk or trans men. This is whom we refer to with the term 'womxn'.

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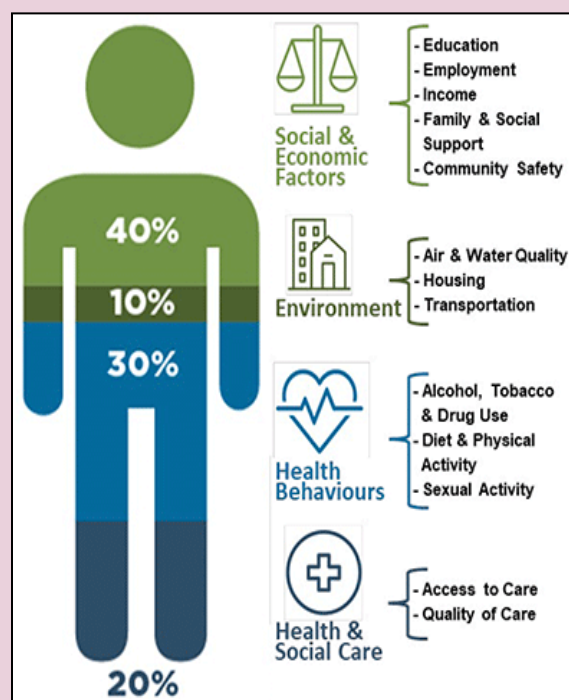
Why Are We Launching this Initiative?

Womxn of African descent(WAD) aspire to live healthy and fulfilling lives. They are invaluable and contribute immensely to families, communities, organisations and society in Scotland as parents, leaders, students, innovators, colleagues and friends. WAD desire positive pregnancies and births and to raise their children in healthy communities. Yet they experience inequities during and after pregnancy and birth, which are preventable, unfair and unjust.

Social determinants of health(SDH) refer to the conditions and structures in which we are born, grow up, are educated, work and die. As illustrated in the diagram, these SDH have the most significant impact(80%) on health outcomes.

In 2023, artificial power dynamics in society continue to structure access to SDH (nutrition, environmental hazards, housing, employment, health access, etc.) through the life course and across generations for WAD. WAD and their families face disproportionate exposure to negative SDH, representing manifestations of [systemic racism](#) such as economic deprivation, isolation, unstable housing & migration status, environmental toxins, gender-based violence, differential treatment during interaction within criminal justice systems and institutional racism.

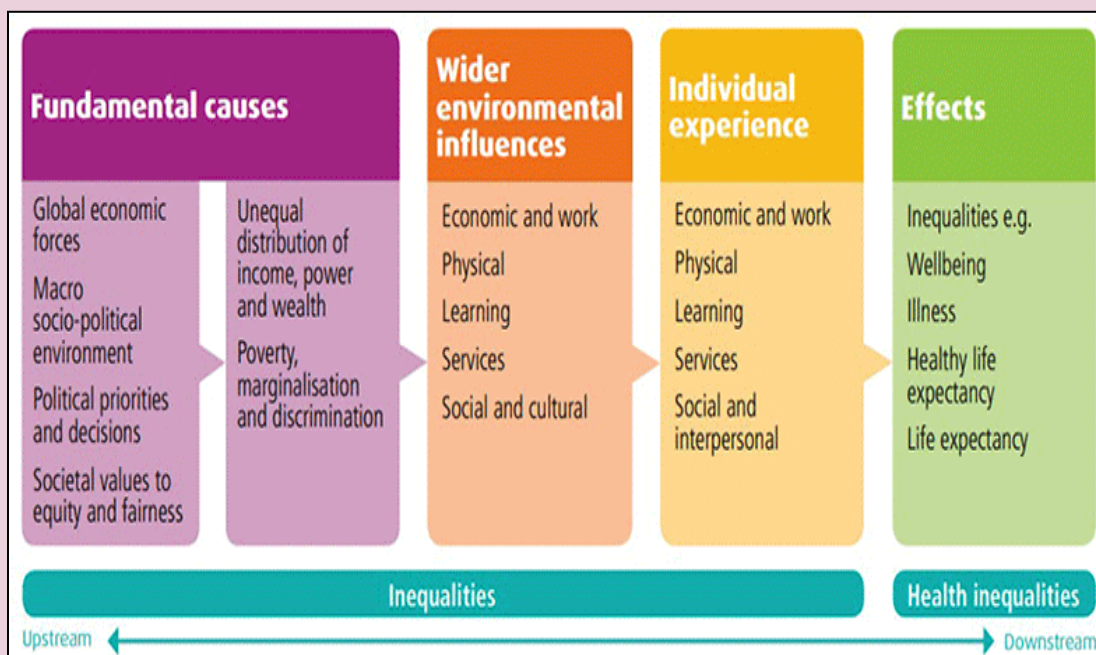
[King's Fund A Vision for Population Health](#)



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WAD experience adverse maternal and newborn outcomes, including [near misses \(morbidity\)](#), [deaths \(mortality\)](#) and [negative experiences](#) whilst accessing care due to [discrimination, racism and disrespect](#) when accessing health & social services. This results in subsequent distrust of and disengagement with health & social services.



[Public Health Scotland](#)

Research has demonstrated a correlation between [exposure to chronic stressors of systemic, institutional and interpersonal racism](#), increased allostatic load, biological weathering and increased risk of metabolic disease. These stressful experiences may also increase health-seeking and engaging behaviours that do not promote health and well-being.

Current research and rhetoric around racial and ethnic equity misrepresent causes of health inequities by focusing on biological essentialism, promoting the notion that Black and Brown bodies are broken and different. The subliminal message from society normalises pathology within Black and Brown bodies such that we do not expect racially minoritised womxn to survive, let alone thrive. This ahistorical damage-centred approach distracts from the social constructionist [nature of race](#) and [systemic racism](#),

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which is rooted in enduring systems of oppression, including eugenics, slavery and colonisation that continue to impact minoritised communities.

What Are the Specific Objectives of this Initiative?

This initiative, therefore, will focus on empowering collective positive action for health and self-advocacy in communities before people engage with health and social systems.

AIM: This initiative specifically aims to:

1. Increase valued participation of WAD in the Lothian Maternity Voices Partnership
2. Use a community education model to promote bi-directional learning between WAD service users and NHS maternity service providers.
3. Explore consensus on co-production within WAD communities, which may facilitate beneficial co-design for advocacy, policy, research and clinical governance work with NHS Lothian.
4. Encourage reflexive learning for future pilots in other minoritised communities also impacted by maternity inequities.

Our actions and reflections will be informed by reproductive justice frameworks, Black Afro-feminism and community-based participatory praxis of coproduction and reflexive learning. We are guided by collectively agreed unifying principles within our communities, including

- Ubuntu- *I am because we are.*
- Empowerment through hope
- Led by womxn of African descent
- Cultural safety (reflexivity + humility)
- Life course & intergenerational approach
- A focus on asset framing- not
- damage-centeredness
- Sustainability that ensures longevity
- Trauma-informed approaches
- Adding value to our communities
- A non-extractive approach

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What Kinds of Community Education Workshops Will be Offered?

The workshops are free to attend and will be held in person and online between November 2023 and March 2024.

Food and travel reimbursement will be provided for all participants who attend in person. The workshops will be held in a safe, welcoming and child-friendly environment. The community education workshops will focus on issues that disproportionately impact African-descent communities and reflect frequently asked questions from WAD within Lothian.

Examples of subjects that will be covered:

- Introduction to the MVP
- Navigating antenatal- postnatal maternity services & pathways
- Providing feedback (compliments & complaints)
- Self-advocacy during pregnancy and labour
- Optimising Preconception Health
- Pregnancy Loss(miscarriage & stillbirth)
- Prevention & Management of Diabetes, Hypertension, Bleeding risk (anaemia, fibroids, endometriosis)
- Pain Relief in Labour
- Postnatal contraception
- Perinatal Mental health & emotional wellbeing
- Exploring Co-production

How Can I Learn More and Receive Updates about Dates of Events?

- Join our mailing list: [Join the mailing list](#)
- Contact KWISA: admin@kwisa.org.uk
- Interested in volunteering? Find out: [How Can I Get Involved?](#)

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Who are KWISA and the MVP?

The ideation, implementation, execution and evaluation of this pilot are led by a multi-disciplinary group of WAD, supported by allies who represent professions that interface with pregnant womxn before, during and after pregnancy inside and outside health and social systems.

[KWISA](#) - is a CIC based in Edinburgh, Scotland, established a decade ago for the development and empowerment of womxn of African descent and their families to achieve their full potential in the community and society in Scotland, the UK and the rest of Africa.



The [MVP](#) is a unique group where the families who use maternity and neonatal services and those working for NHS Lothian review these services. Membership is free and open to anyone interested in pregnancy and birth. The charities and organisations that support families are also represented. The MVP all work together in partnership to make improvements where these are needed. They have six meetings a year, currently held online.