

Title of Report	Black Health Legacy
For Consideration By	Health and Wellbeing Board
Meeting Date	19 March 2026
Classification	Public
<u>Ward(s) Affected</u>	All
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Is this report for:

<input type="checkbox"/>	Information to note	<input type="checkbox"/>	For actions to be allocated
<input checked="" type="checkbox"/>	For Discussion & input	<input type="checkbox"/>	For escalation (if issue is outwith Remit of HWB)
<input type="checkbox"/>	Decision		

Why is the report being brought to the board?

<ul style="list-style-type: none"> • To raise awareness of the Black Health Legacy research programme and to seek endorsement for expanding its work in Hackney • To contribute to delivery of Black Health Legacy across community and voluntary sector and healthcare settings • To run responsive pilots in NHS settings in Hackney based on findings from Black Health Legacy, aimed at reducing health inequalities relevant to health conditions that disproportionately affect people from Black communities
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Provide a summary of the issue here:

<ul style="list-style-type: none"> • People from Black, Black African and Black Caribbean backgrounds are significantly underrepresented in health research, and this perpetuates health inequalities • Black Health Legacy seeks to address this underrepresentation by building a

trusted research study by, with, and for Black communities in the UK

- Black Health Legacy is already making vital discoveries that will contribute to future equitable improvements in healthcare.
- We seek support from Hackney to become a borough-wide partner supporting Black Health Legacy, and responding to its discoveries where they have relevance

Has the report been considered at any other committee meeting of the Council or other stakeholders?

N/A

1. Background

- 1.1. Black, Black African Black Caribbean people are severely under-represented in health research, based on their past experiences of bias, racism and exploitation, and a lack of inclusive research practice.
- 1.2. Despite comprising approximately 15% of the world's population, people from these backgrounds account for less than 1% of participants in major genomic datasets. As a result, genetic and biological factors affecting how diseases are prevented, diagnosed and treated in Black populations remain poorly understood, limiting equitable access to advances in healthcare such as precision medicine.
- 1.3. **Black Health Legacy** has been established specifically to address this inequity. It is a long-term research study funded by a prestigious 8 year Wellcome Discovery Award, led by clinical academics at Queen Mary University of London. It has been developed *by, with and for* Black communities in the UK, studying genetic and non-genetic factors influencing major health conditions including diabetes, hypertension and kidney disease.
- 1.4. The first discovery made by Black Health Legacy challenges how the NHS diagnoses and monitors type 2 diabetes in certain populations. Black Health Legacy researchers studied a minor gene change in the G6PD gene, called G6PD deficiency, which is carried by 1 in 7 Black men, and 1 in 43 Black women in the UK (compared to less than 1 in 10,000 white people).
- 1.5. They discovered that G6PD deficiency has a major impact on the accuracy of the HbA1c blood test, which measures how much glucose has been attached to red blood cells over their 90 day lifespan. Their research showed that people with G6PD deficiency have a faster turnover of red blood cells and this makes HbA1c readings appear lower than they should be.
- 1.6. In the UK, HbA1c is used in over 99% of NHS type 2 diabetes screening, diagnosis, and monitoring. Black Health Legacy researchers have

discovered that men with G6PD deficiency have HbA1c results about 10 mmol/mol lower than people without the condition.

- 1.7. This can delay type 2 diabetes diagnosis by around four years, slow treatment intensification, and increase the risk of complications such as eye and kidney disease. G6PD deficiency is more common in people of African ancestry and is rarely diagnosed in routine adult care. As a result, HbA1c-based diabetes pathways may miss or underestimate type 2 diabetes in Black populations, contributing to poor health outcomes and inequalities relating to the condition.
- 1.8. Hackney, with one of the largest Black African and Black Caribbean populations in England, has the potential to be a major contributor to Black Health Legacy and support its current and future work. Supporting the study provides an opportunity to support inclusive health research, driving equitable advances in health and healthcare to people from these communities. It also provides Hackney residents with opportunities to be at the forefront of these advances, through early adoption and evaluation in local NHS and public health settings.

2. **Current position**

- 2.1. Research and national context: The G6PD–HbA1c diagnostic bias affecting Black populations has only recently been recognised through Black Health Legacy research. Current NHS and NICE diabetes pathways rely on HbA1c thresholds and do not account for this bias. G6PD deficiency is rarely diagnosed - less than 1 in 50 people with the condition know they have it, and there is limited evidence on how best to identify and manage affected individuals
- 2.2. There remains a major evidence gap because Black populations are under-represented in genomic and precision medicine research globally. Without dedicated studies such as Black Health Legacy, further discoveries relevant to diagnosis, treatment and prevention in Black communities will not occur.
- 2.3. North East London has been identified nationally as a suitable region to support Black Health Legacy going forwards, and to contribute to further research and pilot implementation of G6PD testing and alternative approaches to the use of HbA1c in G6PD-deficient individuals.
- 2.4. Hackney has a large population eligible to join Black Health Legacy, and significant inequalities in the outcomes from the health conditions it is studying. There has been wide-ranging enthusiasm for Black Health Legacy and support from multiple local authority and NHS partners, however there is no formal borough-wide support for Black Health Legacy, and the potential for community-led research participation is not yet fully harnessed.

3. **Key facts and/or data**

Global research inequity

- Black African and Black Caribbean populations ≈15% of world population, but are less than 1% of participants in major global genomic studies, resulting in a

lack of discovery relevant to Black populations and risk of widening inequity in precision medicine

Black Health Legacy

- A health and genomic research programme that seeks to engage and recruit up to 100,000 Black participants in the UK.
- It is designed to enable further discoveries in health conditions that disproportionately affect people from Black communities, and it is built on a trusted community partnership model.
- It has already identified that HbA1c in 1 in 7 men with G6PD deficiency is ≈ 10 mmol/mol lower for a given glucose level, and this leads to a ~ 4 -year delay in type 2 diabetes diagnosis and faster progression to disease complications.

Hackney relevance

- $\approx 30\%$ Black population, with type 2 diabetes prevalence and complications higher in Black residents
- There is high suitability for recruitment and partnership with Black Health Legacy

4. Conclusions

- 4.1. The G6PD–HbA1c discovery illustrates how under-representation of Black populations in biomedical research can lead directly to inequitable diagnosis and management of conditions like type 2 diabetes. Without Black Health Legacy research, this major driver of diabetes inequality would likely have remained unrecognised.
- 4.2. Hackney's population profile means residents are disproportionately affected by both:
 - the G6PD-related diagnostic bias in diabetes
 - the wider lack of research evidence relevant to Black health
- 4.3. Black Health Legacy provides the essential infrastructure to address both issues and a unique opportunity for Hackney. It is currently the only large-scale UK study specifically designed to redress genomic under-representation of Black communities and enable equitable precision medicine.
- 4.4. Supporting and adopting Black Health Legacy locally would allow Hackney to:
 - contribute to research that directly benefits its residents
 - address diagnostic inequities in type 2 diabetes from G6PD deficiency
 - enable further discoveries relevant to health conditions that disproportionately impact Black people
 - strengthen trust and participation in research
 - position Hackney as a national leader in inclusive health research that supports equitable precision health

5. **Recommendations**

The Health and Wellbeing Board is asked to:

- A. **Support Hackney formally adopting and partnering with Black Health Legacy**, including community engagement, recruitment and local collaboration.
- B. **Encourage system partners** (NEL ICS, NHS providers, primary care, public health and VCS organisations) to contribute to Black Health Legacy through opportunities for engagement and recruitment
- C. **Position Hackney as a leading borough** in supporting community-led genomic research addressing Black health inequalities.
- D. **Contribute to further research** on the equitable diagnosis of type 2 diabetes in Black people in primary care

6. **Policy Context**

Please detail which, if any, of the Health & Wellbeing Strategy priorities this report relates to?

<input type="checkbox"/>	Improving mental health
<input type="checkbox"/>	Increasing social connection
<input type="checkbox"/>	Supporting greater financial security
<input type="checkbox"/>	All of the above

Please detail which, if any, of the Health & Wellbeing Strategy 'Ways of Working' this report relates to?

<input checked="" type="checkbox"/>	Strengthening our communities
<input checked="" type="checkbox"/>	Creating, supporting and working with volunteer and peer roles
<input checked="" type="checkbox"/>	Collaborations and partnerships: including at a neighbourhood level
<input checked="" type="checkbox"/>	Making the best of community resources
<input type="checkbox"/>	All of the above

7. **Equality Impact Assessment (EIA)**

Has an EIA been conducted for this work?

<input type="checkbox"/>	Yes
<input checked="" type="checkbox"/>	No

8. **Consultation**

Has public, service user, patient feedback/consultation informed the recommendations of this report?

<input checked="" type="checkbox"/>	Yes
<input type="checkbox"/>	No

Have the relevant members/ organisations and officers been consulted on the recommendations in this report?

<input checked="" type="checkbox"/>	Yes
<input type="checkbox"/>	No

9. **Risk Assessment**

Text

10. **Sustainability**

Text

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Appendices	N/A