

**INVITATION TO TENDER**

**For:**

**Identification and assessment of ethnic health inequalities that  
exist within the Genomic Medicine Service**

**Date: March 2024**

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## About the NHS Race and Health Observatory

The NHS Race and Health Observatory ('the Observatory') is an independent organisation, set up to explore ethnic inequalities in access to healthcare, experiences of healthcare, health outcomes, and inequalities experienced by black and minority ethnic members of the health and care workforce. In doing so, it assesses aspirations in these areas as outlined in national healthcare policy, including those set-out in the NHS Long Term Plan. It is a proactive investigator, providing strong recommendations that inform policymaking and facilitate change. It is evidence-driven and solution-focused.

The Observatory is supported by NHS England and hosted by NHS Confederation. Its board and team are independent, and dictate their own direction and areas of focus. The Observatory has three main functions:

- facilitating new, high-quality, and innovative research and evidence
- making strategic policy recommendations for change.
- supporting the practical implementation of those recommendations.

Among our many priority areas are those concerning the future of medicine – genomics, precision medicine, and artificial intelligence among others.

## Scope of the work

### *Background*

In 2022, the Observatory published *Ethnic Inequalities in Healthcare: A Rapid Evidence Review*<sup>1</sup>. This report highlighted concerns that services such as genetic testing and counselling are not equally accessible for ethnic minority patients as they are for the White majority population in the UK<sup>2</sup>. It has also been acknowledged that many large genome wide association (GWA) studies lack ethnic diversity which may then limit the utility and validity of conclusions that can be drawn from these datasets<sup>3,4</sup>.

In 2022, the Observatory commissioned a review into ethnic health inequalities in precision medicine and the future of healthcare<sup>5</sup>. This review included:

- A policy review to understand the aspects and priorities of current approach to ethnic equity in the development and implementation of precision medicine services.
- An academic evidence synthesis review to identify health inequalities in precision medicine.

- An assessment of the views of a variety of stakeholders (clinicians, academics, policymakers, public) regarding knowledge, understanding, attitudes and practice in promoting diverse access to precision medicine services, barriers/facilitators to access and service needs for better implementation.
- Exploration of the views of individuals representing different ethnic groups on knowledge, understanding and engagement with precision medicine services, and how access could be more equitable.
- Identification of current access to genomic medicine services by minority groups.

The NHS Genomic Medicine Service (NHS GMS) was commissioned in October 2018 by NHS England<sup>6</sup>. This service aims to deliver consolidated, state of the art, high throughput and high-quality genomic testing (including both genome and exome sequencing) with equity of access for patients affected by rare diseases and cancer. Early findings from the Observatory's precision medicine review have identified key areas of improvement, including inequalities in access for Black and minority ethnic patients and poor ethnicity data collection within the wider Genomic Medicine Service. A national network of 7 NHS Genomic Medicine Service Alliances (GMSAs) was set up in 2020 to support the systematic embedding of genomics into routine clinical care and the rapid adoption of scientific advances through collaborative partnership working across disciplines and geographies.

Additionally, preliminary analysis from the Observatory has identified the lack of health equity data in the provision and utilisation of genetic services. Initial recommendations of the precision medicine review detail the need to improve collaboration across the seven NHS Genomic Medicine Service Alliances; enhance ethnicity data sharing between NHS Trusts, genomic service, and Genomic Laboratory Hubs (GLHs); standardise of ethnicity recording; and develop a national EDI framework.

Structural and systemic barriers limit genetic diagnosis among those from Black and minority ethnic patients,<sup>7, 8</sup> including failure to suspect or recognise genetic disorders from these communities<sup>9</sup>, reduced referral rates for genetic testing, challenges in interpretation results test results due to lack of ancestral diversity in the reference genome<sup>10</sup>, and low referral rates to rare disease research programs<sup>11</sup>.

A limited understanding of the ethnicity profiles of those accessing genomic services risks excluding communities in the collection and use of their genomic data. The overrepresentation of European ancestral populations in genomic databases has resulted in misdiagnoses, poor understanding of conditions, and inconsistent delivery of care, as well as mistrust. As a result, genomic medicine may not always benefit all people equally.

Prioritising diversity in genomic research can lead to a range of benefits including new understanding of genes that underlie diseases, new treatments for a more diverse range of people populations, more accurate reading of a person's risk of developing a specific disease, and the design of a clinical management strategy tailored to individuals.

The Observatory will be partnering with NHS England to expand this programme to identify and assess inequalities that may exist within the NHS GMS. Collaborating with the NHS Race and Health Observatory will allow for a unique way of working, whereby NHS England can address the challenges from an internal organisational perspective, while using the Observatory's expertise to identify and assess inequalities that exist within the selected GMSA geographies, working with live NHS services being offered nationally.

This unique partnership centres on identifying and understanding racial and ethnic disparities in the access and provision of genomic services and to utilise implementation science to address disparities in genomic medicine.

#### *Project outline*

This invitation to tender encompasses a mixed-methods research project employing qualitative and quantitative approaches to provide a richer, deeper insight into the topic area, generating more knowledge, and increasing the validity of the findings<sup>12</sup>. Overall, this programme will comprise of five work packages (WP), a subset of which we are seeking external collaborators to support in the delivery of. Bidding organisations will be expected to work closely with the NHS Genomics Unit and the Observatory's Senior Clinical Advisor.

The aims and work packages of this project are to:

1. Identify current access, utilisation, and diagnostic performance of the genomic medicine services by ethnic minority groups (WP1 – Delivered exclusively by NHS England in partnership with the National Disease Registration Service).
2. Understand areas of potential racial and ethnic bias along the patient pathway within selected GMSA geographies (WP2 – Delivered exclusively by bidding organisation)
3. Review current initiatives and quality improvement programmes being undertaken to address existing ethnic health inequalities in the NHS GMS (WP3 – Delivered exclusively by bidding organisation).
4. Develop a common framework by which other GMSAs and wider NHS GMS - supporting services can review the potential bias of their service as a mechanism for quality improvement (WP4 – Delivered exclusively by bidding organisation)
5. Develop and implement impactful case study solutions to improve the delivery of genomic medicine across the NHS GMS, particularly for minority ethnic communities (WP5 – Delivered in collaboration with the bidding organisation, NHS England and the NHS Race & Health Observatory).

**WP1:** Identify current access, utilisation, and diagnostic performance of the genomic medicine services by ethnic minority groups. This will be informed by disease areas including but not limited to prostate cancer, Lynch Syndrome and certain rare diseases.

**WP 2:** Understand areas of potential racial and ethnic bias along the patient pathway within selected GMSAs

- Informed by the findings of WP1, qualitative approaches will be used to understand the patient pathways within the GMSA geography to identify specific areas of bias, but particularly ethnic bias. It is expected that multiple qualitative methods will be utilised including, but not limited to semi-structured interviews, focus groups and ethnographic approaches with services users as well as healthcare staff. Combining analytical evidence, with user and service design approaches pathways to root out potential sources of bias will be explored.
- Suggested approaches:
  - i. In order to understand the patient perspective, this project will seek out individuals from a diverse range of Black, Asian and minority ethnic groups with lived experience of utilising genomic services and their navigation through the investigative pathways.
  - ii. Interviewing clinicians, including genetic specialists, rare disease specialists and counsellors tasked with delivering services which include genetic testing to understand how their experience of potential ethnic bias in the delivery of genomic services.
  - iii. Observations of clinical encounters to examine the interaction between healthcare professionals and patients, alongside interviews with the professionals and patients to understand the processes and practices taking place when consenting for and returning genomic test results.

**WP3:** Review current initiatives and quality improvement programmes being undertaken to address existing ethnic health inequalities in the NHS GMS. As part of their Equality, Diversity, and Inclusion programmes of work<sup>13</sup>, GMSAs nationally have begun to implement strategies to improve inclusion in genomic services for patients. This WP aims to identify areas of good practice to share, and common areas of deficit where a system-wide approach may be beneficial.

**WP4:** Develop a common framework by which other GMSAs and wider NHS GMS can review the potential bias of their service as a mechanism for quality improvement.

- Using an implementation science approach, the findings from WP1, 2 and 3 will be used to develop a flexible approach to improve the delivery of genomic services and patient pathways for patients from black and minority ethnic communities.

- This will be undertaken in conjunction with key stakeholders from organisations (GMSAs and NHSE) tasked with designing and delivering genomic services across the selected GMSA.
- Enhanced delivery of genetic medicine services to reduce ethnic bias may encompass the following areas: Coaching; teaching and facilitation, technical interventions (e.g. to digital systems, pipelines), and process changes.

**WP5:** Develop and implement impactful case study solutions to improve the delivery of genomic medicine services across the GMSAs and wider NHS GMS particularly for minority ethnic communities (WP5 – Delivered by NHS England and the Race & Health Observatory).

### *Outputs*

On completion of the research period, the following should be produced:

- Detailed findings of the research including:
  - i. Consideration of the role that structural and institutional racism plays in informing the utilisation of genomic medicine services.
  - ii. Identification of specific ethnic biases in genomic medicine pathways.
  - iii. Development of strategies to improve the delivery of genomic medicine and reduce ethnic inequality in the access and delivery of genomic medicine services.
  - iv. Evidence-based and co-designed recommendations for practice including for policy change which can be applied across the NHS GMS.
- A high-level summary report, including recommendations for policy, practice, and research.
- An interim report to be produced at the mid-way point of the project.
- Presentation of findings to the Observatory and its academic reference group at the end of research period.

### *Detailed specifications*

- The initial research period will be 18 months from the date of award, with a further 4 weeks for review and sign off. Longer periods may be considered if justification for the longer timescale can be provided.
- The programme of work should include extensive and meaningful patient engagement at all stages, including initial scoping and assurance of final conclusions and recommendations.
- Quality criteria should be applied to evidence including, where appropriate, evidence of user-validation and stakeholder validity.

- The report will be for external publication by the NHS Race and Health Observatory, using the Observatory and NHS England branding, but also including the logo of the contracted organisation.
- We welcome bids up to £120, 000 (exclusive of VAT). Higher value bids may be considered if adequate justification can be given for the additional amount.

### References

1. NHS Race and Health Observatory. *Ethnic Inequalities in Healthcare: A Rapid Evidence Review*. [https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report\\_v.7.pdf](https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf). [Accessed 18<sup>th</sup> June 2022].
2. Hann KEJ, Freeman M, Fraser L, *et al*. Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. *BMC Public Health*. 2017;17(1):503. doi:10.1186/s12889-017-4375-8
3. Sharif SM, Blyth M, Ahmed M, *et al*. Enhancing inclusion of diverse populations in genomics: A competence framework. *J Genet Couns*. 2020;29(2):282-292. doi:10.1002/jgc4.1263 21.
4. Sirugo G, Williams SM, Tishkoff SA. The Missing Diversity in Human Genetic Studies. *Cell*. 2019;177(1):26-31. doi:10.1016/J.CELL.2019.02.048
5. NHS Race and Health Observatory. *Invitation to Tender: A Review into Ethnic Health Inequalities in Precision Medicine and the Future of Healthcare*. <https://www.nhsrho.org/news/invitation-to-tender-a-review-into-ethnic-health-inequalities-in-precision-medicine-and-the-future-of-healthcare/>. [Accessed 14<sup>th</sup> June 2022].
6. NHS England. *NHS Genomic Medicine Service Alliances to help embed genomics into patient care pathways*. <https://www.england.nhs.uk/blog/nhs-genomic-medicine-service-alliances-to-help-embed-genomics-into-patient-care-pathways/> [Accessed 14<sup>th</sup> June 2022].
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9. Muenke M, Adeyemo A, Kruszka P. An electronic atlas of human malformation syndromes in diverse populations. *Genet Med*. 2016;18(11):1085. doi: 10.1038/gim.2016.3

10. Manrai AK, Funke BH, Rehm HL, Olesen MS, Maron BA, Szolovits P, et al. Genetic Misdiagnoses and the Potential for Health Disparities. *N Engl J Med.* 2016;375(7):655-65. doi: 10.1056/NEJMsa1507092.
11. Young JL, Halley MC, Anguiano B, Fernandez L, Bernstein JA, Wheeler MT, et al. Beyond race: recruitment of diverse participants in clinical genomics research for rare disease. *Front Genet.* 2022;13:949422. doi: 10.3389/fgene.2022.949422
12. Moran-Ellis J, Alexander VD, Cronin A, et al. Triangulation and integration: processes, claims and implications. *Qualitative Research.* 2006;6(1):45–59. doi: 10.1177/1468794106058870.
13. South East Genomics Medicine Service Alliance. Equality, Diversity and Inclusion Strategy 2022-2024. <https://southeastgenomics.nhs.uk/wp-content/uploads/2022/08/South-East-GMSA-EDI-Strategy-April-2022.pdf>[accessed 4th July 2023]

### **Tender submission**

Your tender submission should be organised under the following headings:

#### **‘Project plan’ to include:**

- An introduction illustrating your understanding of the brief, and of the role that race and racism play in determining differential experience and outcomes.
- A summary project plan including details of your proposed methodology and approach to community engagement.
- A timeline including key dates to demonstrate how you would meet the proposed deadline.
- An indication of how much input and capacity would be required from the Observatory team.
- Details of key personnel who will be involved in the project.
- Key ways in which you will work with community partners to ensure patient and public engagement.
- Key risks and mitigating actions for the project.

#### **‘Fee proposal’ to include:**

- Costings for the work including VAT.
- A detailed budget covering both personnel costs and any non-pay expenses.
- The costs of any elements of the work that would be provided by another company/freelance staff.

#### **‘Company information’ to include:**

- A brief outline your values, structure, size, and capabilities in general.

- Detail of any elements of the work that would be provided by another company/freelance staff.
- An explanation of the unique benefit you will bring to this work.
- Details of how you propose to ensure GDPR compliance, as appropriate.

**‘Supporting Evidence’ to include:**

- Examples of at least two similar tenders you have won and delivered.
- The details of two previous clients (preferably not for profit) that we can contact for reference purposes (references will be taken up for firms shortlisted).
- Two examples of written work completed by the primary proposed authors.
- A completed equalities questionnaire (see schedule 1).

### Selection criteria

We will rank tenders on the basis of:

1. Overall fit to requirements of the brief and proposed methods.
2. A proven track record of impactful high quality previous work in the area.
3. Relevant experience of team, including a demonstration of cultural competence, understanding of precision medicine, and an ability to engage with issues around ethnic health inequality and racism.
4. Value for money to the Observatory.
5. Your approach to equality, diversity and inclusion.

### Key Dates

ITT released	20 <sup>th</sup> March 2024
Deadline for bids	14 <sup>th</sup> May 2024
Potential follow-up interviews	w/c 3 <sup>rd</sup> June 2024
Contract awarded	1 <sup>st</sup> July 2024
Interim report	1 <sup>st</sup> April 2025
Draft full report	1 <sup>st</sup> December 2025
Final report	10 <sup>th</sup> January 2026

**Instructions for the return of the tenders**

**Tenders should be submitted by email to [info@nhsrho.org](mailto:info@nhsrho.org)**

Tender ref: RHO\_ GEGMS

Tenders must be received by end of Deadline for bids 14<sup>th</sup> May 2024. Tenders received after this date will not be considered.

It is incumbent on tenders to ensure they have all of the information required for the preparation of their tenders.

**Further information about this tender can be obtained from:**

Name	Dr Veline L'Esperance
Title	Senior Clinical Advisor
Email address	<a href="mailto:info@nhsrho.org">info@nhsrho.org</a>

## Schedule 1

### Equalities questionnaire

This questionnaire must be completed satisfactorily in order for any company to be considered to tender for this NHS Confederation contract. In most cases, references to legislation below refer to the Equality Act 2010.

1. Is it your policy as an employer and as a service provider to comply with your statutory obligations under the equality legislation, which applies to Great Britain, or equivalent legislation in the countries in which your firm employs staff?

Yes                  No

2. Accordingly, is it your practice not to discriminate directly or indirectly in breach of equality legislation which applies in Great Britain and legislation in the countries in which your firm employs staff:

- In relation to decisions to recruit, select, remunerate, train, transfer and promote employees?

Yes                  No

- In relation to delivering services?

Yes                  No

3. Do you have a written equality policy?

Yes                  No

4. Does your equality policy cover:

- Recruitment, selection, training, promotion, discipline and dismissal?

Yes                  No

- Victimisation, discrimination and harassment making it clear that these are disciplinary offences?

Yes                      No

- Identify the senior position for responsibility for the policy and its effective implementation?

Yes                      No

5. Is your policy on equality set out:

- In documents available and communicated to employees, managers, recognised trade unions or other representative groups?

Yes                      No

- In recruitment advertisements or other literature?

Yes                      No

- In materials promoting your services?

Yes                      No

Please evidence all questions.

If you answered NO to any part of questions 4 or 5, can you provide (and if so, please do) other evidence to show how you promote equalities in employment and service delivery.

6. In the last three years, have any findings of unlawful discrimination been made against your firm by the Employment Tribunal, the Employment Appeal Tribunal or any other court or in comparable proceedings in any other jurisdiction?

Yes                      No

7. In the last three years, has any contract with your organisation been terminated on grounds of your failure to comply with:

- Legislation prohibiting discrimination; or

Yes                      No

- Contract conditions relating to equality in the provision of services

Yes                      No

8. In the last three years, has your firm been the subject of formal investigations by the Equality and Human Rights Commission or a comparable body, on grounds of alleged unlawful discrimination?

Yes                      No

9. If the answer to question 6 and 7 is YES, or, in relation to question 8, a finding adverse to your organisation has been made, what steps have you taken as a result of that finding? Please summarise the details below and provide full details as an attachment.

10. If you are not currently subject to UK employment law, please supply details of your experience in complying with equivalent legislation that is designed to eliminate discrimination and to promote equality of opportunity. List any attached documents.

### **Guidance in answering the equality questionnaire**

When completing the questionnaire, all companies must answer each question fully and supply any documentary evidence requested. Failure to fully answer each question or failure to submit any documentary evidence required may lead the NHS Confederation to consider the answer unsatisfactory.

### **Question 1 and 2**

If your firm has implemented an effective equality policy, you will be able to answer yes to these questions. You will be able to confirm your answers by submitting your equality policy and supporting evidence as for as part of this section.

### **Question 3 and 4**

You will need to submit a copy of your firm's equality policy. You will need to ensure that your policy covers:

- Recruitment, selection, training, promotion, discipline and dismissal
- Victimisation, discrimination and harassment
- Identifies the senior position responsibly for the policy

### **Question 5**

Documents available and method of communication to staff. You will be required to submit examples of any documents, which explain your firm's policies in respect of recruitment, selection, remuneration, training and promotion outside of the equality policy asked for in Question 3 and 4.

You will also need evidence of how your firm has communicated this document to staff i.e. notice boards or issue individual employees with a copy. There is no prescribed evidence here. You will need to submit whatever documents your firm uses for these purposes.

In recruitment advertisements or other literature, you will need to submit evidence that makes public your firm's commitment to equality in employment and service delivery.

Small firms may not have detailed procedures, but you must ensure that evidence is provided which demonstrates that personnel operate in accordance with a written equality policy that includes:

- Open recruitment practices such as using job centres and local newspapers to advertise vacancies
- Instructions about how the firm ensures that all job applicants are treated fairly.

In material promoting your services This relates to how your firm provides information in materials promoting your services e.g. in different languages, making information accessible to people with hearing and visual impairment and physical access for disabled users.

#### **Question 6**

This question's concern is whether any court or industrial tribunal has found your firm guilty of unlawful discrimination in the last three years. It is important to be honest with your answers. The NHS Confederation may check your responses. If the answer is yes, you may wish to insert additional information which details the actions your firm has undertaken to prevent a repeat occurrence.

Answering yes will not automatically mean that you do not get the contract; you need to ensure that the NHS Confederation feels confident that you have sufficient measures put in place to prevent a re-occurrence.

#### **Question 7**

This question's concern is whether your firm has ever had a contract terminated for noncompliance with equality legislation or equality contract conditions. If the answer is yes, your firm may wish to submit additional information which details the actions they have taken to prevent a repeat occurrence.

#### **Question 8**

This question asks whether your firm has had any investigation carried out, whatever the outcome. The NHS Confederation can check a contractor's answer from lists that the CRE and EOC produce, so please be honest. The NHS Confederation is aware that because a firm has been investigated does not mean that it is guilty of discrimination. The result of the investigation will be taken into account when assessing your firm's answers to the questionnaire.

#### **Question 9**

If your firm has been found guilty of unlawful discrimination, you will need to provide evidence that details the steps your firm has taken to correct the situation. The Court, Industrial Tribunal or CRE will have made recommendations about steps your firm should take to eliminate the discrimination. If no action or inadequate action has been taken in this respect, only then will your firm be considered refusal onto the tender list.

#### **Question 10**

If your firm is not subject to UK employment law you must ensure that you supply details of equivalent legislation that you adhere to.