

Classification: Official

Publication approval reference: PAR1129

NHS Genomic Medicine Service Research Collaborative Steering Committee

Terms of reference

5 January 2022, Version 1

1. Background

In October 2018, NHS England began to mobilise the NHS Genomic Medicine Service (GMS). The NHS GMS will help ensure consistent and equitable care for England's 55 million population through the implementation of a single national genomic test directory, covering the full diagnostic repertoire of whole genome sequencing (WGS) and non-WGS testing for: rare and inherited disorders, cancer, and over time other areas such as pharmacogenomics. The NHS GMS will also enable the collection of genomic and clinical data for WGS and non-WGS testing as part of routine clinical care.

A key aim of the NHS GMS, in line with the NHS Long Term Plan commitment, is to support research and development including through continuing to develop a single genomic knowledgebase to allow research on a national scale, and ensure alignment with national research aims.

The NHS GMS Research Collaborative has been convened to:

- Enable collaborative working to support and enable increasing volumes of high-quality genomic research in the NHS.
- Facilitate access to new genomic samples from the NHS GMS and enable the research to be delivered at scale and speed.
- Identify the need and opportunities to support further development of genomic medicine in the NHS.

- Receive and review proposals, creative collaborative bids, support identification of unmet need, and support commissioning through evaluation projects and respond to emerging technologies.

2. Purpose

The purpose of the Steering Committee is to rapidly evaluate the capacity, capability, resource, scientific merit and benefit to the NHS of the NHS GMS to support research.

The Steering Committee will:

- Appoint members to the expert review panel to review early feedback submissions to help determine whether a potential research opportunity could be delivered in the GMS.
- Review the feasibility of carrying out genomic research that includes requirements for participation of the NHS GMS, by facilitating applications submitted via Genomics England (for studies that require recontact, trials, additional samples or for genomic data not held in the library), and reviewing research proposals.
- Consider and select sites for facilitation of approved research projects within the GMS.
- Continually review the capacity for research within the NHS GMS.
- Review the progress of ongoing research activities.

The Steering Committee will not be responsible for reviewing access to genomic data in the library. This will continue to be managed through existing governance structures coordinated by Genomics England.

3. Membership

The membership of the Steering Committee is:

- co-chairs on behalf of NHS England and NHS Improvement and Genomics England
- one representative from each NHS genomic laboratory hub
- one representative from each NHS GMS alliance
- NHS England representatives
- Genomics England representatives
- two NIHR representative(s)
- devolved nations (tbc – representatives appointed as appropriate following committee establishment).

A list of the current membership is provided in Annex 1. Steering Committee members are not permitted to nominate a deputy for attendance at Steering Committee meetings. Absence from multiple Steering Committee meetings may result in dismissal from the Committee and an alternative representative to be appointed.

4. Quorum

A minimum of 50% of members and one member from each region must be present for the meeting to be deemed quorate.

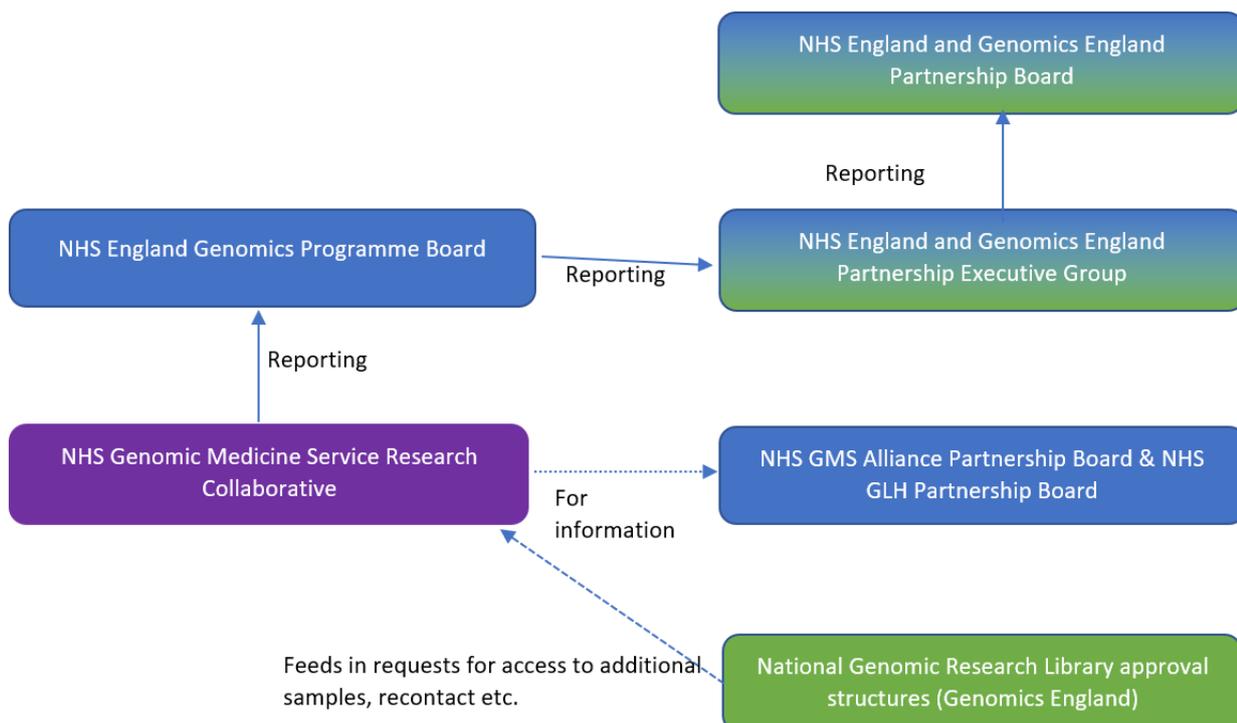
5. Frequency of meetings

The Steering Committee will meet monthly. Where possible the first meeting of each quarter will be held in person. All other meetings will be held via videoconference. The frequency of meetings will be reviewed and revised by the Steering Committee as appropriate.

6. Governance and administration

Secretariat for the Steering Committee will be jointly provided by NHS England and NHS Improvement, and Genomics England.

The Steering Committee, as part of the NHS GMS Research Collaborative, will report to the NHS England and NHS Improvement Genomics Programme Board and NHS England and NHS Improvement Partnership Executive Group, and to the NHS England and NHS Improvement GLH Partnership Board for information.



7. Declarations of interest

Declarations of interest from committee members must be made through the NHS England and NHS Improvement Register of Interests and to the secretariat. A copy of declarations of interest should be declared in writing to the secretariat. A conflict of interest register will be maintained by the Secretariat. Any declarations of interest must also be provided verbally at the start of each committee meeting and will be recorded in the minutes. Appropriate action will be taken by the chair at each meeting in relation to any conflicts of interest.

8. Terms of reference review

Terms of reference will be reviewed on an annual basis and approved at a meeting of the Steering Committee.

Annex 1 – NHS GMS Research Collaborative Steering Committee membership 2021/22

Name	Affiliation
Professor Dame Sue Hill (Co-Chair)	Chief Scientific Officer and Senior Responsible Officer for Genomics, NHS England and NHS Improvement
Chris Wigley (Co-Chair)	Chief Executive Officer, Genomics England
Emma Baple	NHS South West GLH
Andrew Mumford	NHS South West GMS Alliance
Deborah Morris-Rosedahl	NHS South East GLH
Vacant	NHS South East GMS Alliance
Michael Hubank	NHS North Thames GLH
Claire Shovlin	NHS North Thames GMS Alliance
Hana Lango Allen	NHS East GLH
Maria Koufali	NHS East GMS Alliance
Nick Cross	NHS Central and South GLH
Julian Knight	NHS Central and South GMS Alliance
Robert Taylor	NHS North East and Yorkshire GLH
Meena Balasubramanian	NHS North East and Yorkshire GMS Alliance
Emma McCann	NHS North West GLH
Bernard Keavney	NHS North West GMS Alliance
Philip Evans	National Institute for Health Research
Eamonn Maher	National Institute for Health Research
Sine Littlewood	National Institute for Health Research
Jonathan Graves	Department for Health and Social Care (Observer)

Additional members from NHS England and NHS Improvement and Genomics England attend meetings and support the operation and management of the NHS GMS Research Collaborative Steering Committee.