

Genomic Medicine Service Alliances and role of nurses and midwives within the new structure

Update for Chief Nurses and Heads of Midwifery July 2020

Summary of Actions:

All Chief Nurses and Heads of Midwifery should:

- Be aware of the NHS Genomic Medicine Service (GMS), implications for nurses and midwives and the development of GMS Alliances.
- Identify members of their team with specialist expertise in genomics, (e.g. currently
 practicing in genomics service; via taught courses in genomics) and encourage
 them to be actively involved in GMS Alliance nursing and midwifery strategic plans.
- Support the development and delivery of GMS Alliance nursing and midwifery transformation programmes via regional and integrated care system (ICS) level nursing and midwifery networks.
- Encourage members of their nursing and midwifery teams to learn about genomics and personalised medicine via: https://www.genomicseducation.hee.nhs.uk/.

In addition, Hospital Chief Nurses and Heads of Midwifery should:

 Liaise with their NHS England and NHS Improvement Regional Chief Nurses and regional Genomic Laboratory Hub Medical Directors for further information on the GMS Alliance application and work collaboratively across the region to provide nursing and midwifery input to the GMS Alliance plans.

NHS Genomic Medicine Service

The landmark 100,000 Genomes Project highlighted the transformative potential of genomics and provided the evidence for systematically implementing whole genome sequencing (WGS) within NHS clinical care.

In October 2018 NHS England and NHS Improvement launched the NHS Genomic Medicine Service (GMS) to embed genomics in NHS care and provide consistent and equitable care for patients and families. It now has six key elements:

- 1. A national genomic testing service delivered through a network of Genomic Laboratory Hubs (GLHs);
- 2. A National Genomic Test Directory defining the testing available within the NHS in England and the technology to deliver it;
- 3. National WGS provision and a supporting informatics infrastructure developed in partnership with Genomics England;
- 4. An integrated clinical genetics service that includes genomic counselling for rare and inherited diseases and cancer:
- 5. Regional infrastructure (GMS Alliances) built on the 100,000 Genomes Project infrastructure, to support the systematic embedding of genomic medicine;
- 6. A national implementation, co-ordination and oversight function within NHS England and NHS Improvement (Genomics Unit).

Provider partnerships within the regions are leading the formation of the GMS Alliance infrastructures; these will submit plans to NHS England and NHS Improvement. COVID-19 has delayed this process and the GMS Alliance infrastructures are now expected to be established in the Autumn 2020, subject to the finalisation of funding arrangements.

Role of Nursing & Midwifery within the NHS GMS

Delivering a new NHS Genomic Medicine Service brings together exciting opportunities with new detailed understanding about peoples' underlying genetic profiles. The development of novel and revolutionary medical treatments will result in personalised medicines which are better suited and tailored to treat the underlying cause with improved outcomes for patients. Delivering this world-class revolutionary service will require new ways of working for the professions. Nurses, midwives and care staff form the largest workforce in the NHS and are well placed to optimise the potential contributions of genomics for improving health. The senior leadership of these professions, in steering the workforce, will be critical to the success of the NHS GMS for patients in England.

System Leadership and Transformation in the NHS GMS

Nurses and midwives will play a key role within the GMS Alliances and across the wider NHS GMS. Each GMS Alliance will develop transformation programmes with projects established for nursing and midwifery, pharmacy and medicine. The senior governance structure for each GMS Alliance should include representation from a chief nurse (or equivalent) from within the region to provide system leadership.

In addition, the new GMS Alliance structures will include a multidisciplinary clinical leadership team, in which lead nurses and midwives with genomics and operational expertise will be crucial in playing a leadership role to mainstream it into healthcare practice.

Chief nurses, particularly those within provider partnership organisations, are requested to be closely involved in the formation and progress of the GMS Alliance and support any appointments to lead nursing/midwifery roles. As the GMS Alliances form, chief nurses/midwives across primary and secondary care are presented with an exciting opportunity to work collaboratively, positioning strong leadership in nursing and midwifery to support the development of genomics in healthcare and delivery of the nursing & midwifery transformation projects. Close links between the GMS Alliance and regional integrated care system (ICS) nursing and midwifery networks will ensure systematic implementation of genomics into workforce plans in end-to-end clinical pathways of care with equitable access for patients. Nurses and midwives have a crucial role in supporting the mainstreaming of genomics into clinical practice.

Hospital Chief Nurses/Midwives are advised to liaise with their NHS England and NHS Improvement Regional Chief Nurse/Midwife and Medical Directors at Genomic Laboratory Hubs within their region for further information and discussion on the infrastructure plans. Support to develop the nursing and midwifery plans and provide further information is available from genomics nursing and midwifery team (see contacts below) and within Appendix 1: Key considerations for GMS Alliances and Development of Nursing and Midwifery Plans.

Nursing & Midwifery Genomics Collaborative Network

GMS Alliance nursing and midwifery system leaders and clinical nursing and midwifery leads with specialist expertise in genomics will be brought together into a national nursing and midwifery genomics collaborative network. NHS England and NHS Improvement, Health

Education England (HEE) Genomics Education Programme, and a range of other partners (still in development) will support the national network.

The network will share best practice, and work to achieve the following:

- 1. Agree a national approach to embed genomics into workforce plans enabling all eligible patients to benefit from the NHS GMS;
- 2. Review NHS service delivery needs to establish what changes in nursing and midwifery workforce skills and requirements are required to meet the demands of a new genomic medicine service
 - Including identifying (as a priority) the high-level gaps in current workforce skills, education, training and development needs
- 3. Work with NHS England and NHS Improvement to support the evaluation of transformation programmes

Framework for delivery

Delivery of the programme will be through collaborative decision making on projects within the footprint of the GMS Alliance. Each GMS Alliance will run multiple priority projects identified locally. Projects (for nursing and midwifery) will be owned and led by teams of nurses and midwives within the localities.

The NHSE/I nursing and midwifery team will link up GMS Alliance projects nationally, operating as a 'national grid', connecting teams, networks, organisations and the wider system, sharing issues and challenges as well as good practice. The NHSE/I team will also support the 7 GMS Alliance Chief Nurse SROs and operational leads with advice on their delivery plans for chosen projects.

The underpinning framework (figure 1) to support embedding genomics into nursing and midwifery practice comprises 3 major pillars of work.

• Pillar 1: Nurse & Midwifery-led genomics projects: Within the 7 GMS Alliances, collaborations of senior nurses and midwives will come together to engage and mobilise clinical teams from across their regions. Aligning clinical practice requirements to service needs, these collaborative groups will aim to support nurses and midwives (which may include health visitors, or AHPs if they are part of the

clinical pathway) as they adopt skills and knowledge to include genomics in their everyday mainstream practices. Using evidence-based methodologies, teams will work with partners (for e.g. local quality improvement and transformation teams, HEE, AHSNs, Cancer Alliances, charities, professional networks, and others) to test changes and embed genomics into clinical practice. Knowledge and case studies will be shared cross-regionally and nationally to illustrate the positive impacts that genomics focussed care pathways have on health outcomes for patients and families.

- Pillar 2: Building capacity and capability across the system. This will be achieved at local, regional and national level using a wide variety of methods to support implementation with an operational focus based on service needs.
- **Pillar 3:** Large scale change methods will be utilised at regional and national level to support the programme. In addition, an ambitious communications strategy will ensure awareness is raised, a strong narrative is developed, and work is shared widely across the system

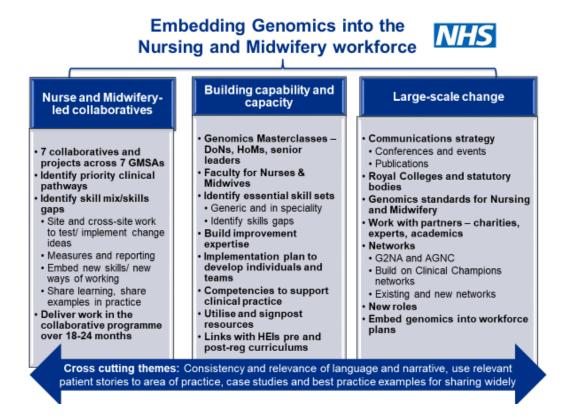


Figure 2: Underpinning framework – incorporating 3 Pillars of work to support embedding genomics into Nursing and Midwifery practice in England

Education and Training

Educational resources and opportunities to learn more about genomics are available from the HEE Genomics Education Programme at https://www.genomicseducation.hee.nhs.uk/. These range from online courses, videos and podcasts through to fully taught courses. Please encourage members of your nursing and midwifery teams to visit the website.

Contacts

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For further information and updates on the NHS GMS you can register as stakeholder for the Genomics Clinical Reference Group https://www.england.nhs.uk/commissioning/spec- services/get-involved/crg-stake-reg/

You can also follow us on Twitter @NHSGMS

Appendix 1: Key Considerations for GMS Alliances and Development of Nursing and Midwifery Transformation Plans

Strategic Leadership

The presence of a chief nurse/midwifery on system leadership at GMS Alliance strategic board level will provide seniority and an inspirational steer for nurses and midwives. A single Chief Nurse SRO, representing all Chief Nurses and nominated locally, will provide the professional system leadership required across the GMSA region. The Chief Nurse SRO will support delivery of identified priorities and the nursing and midwifery transformation programme by:

- Providing a link to senior nursing and midwifery leaders and networks across the region.
- Liaising with Regional Chief Nurses and system leaders at STP/ICS level
- Participating in the national Nursing and midwifery Genomics Collaborative and sharing practice across GMS Alliances.
- Being a member of the Nursing and Midwifery Genomics Collaborative Board chaired by Professor Janice Sigsworth, Director of Nursing Imperial Healthcare NHS Foundation Trust and Professional Lead for the nursing and midwifery genomics programme in England

Operational Leadership

An operational clinical lead nursing/midwifery post/s is recommended as part of the clinical leadership team, with dedicated time to work on delivery of NHS GMS priorities related to the nursing and midwifery transformation programme. Consider:

- Clinical genomics knowledge of the post-holder alongside developed operational skills at senior level to enable delivery of projects
- Support that may be required for the post-holder to further develop their genomics expertise and/or system leadership skills.
- Clinical Lead nurses/midwives will also participate in the national Nursing and Midwifery Genomics Collaborative, sharing practice, supporting collaborations across the GMS Alliances and providing expert advice.
- Identifying and mobilising other nurses and midwives or genomics champions across the region who can help with project delivery

Suggestions to develop Nursing and Midwifery Transformation Programmes

- 1. Map relevant stakeholders and networks for nursing and midwifery across the region and plan an appropriate strategy to engage them with the GMS Alliances and the wider nursing/midwifery programme.
- 2. Undertake a baseline review of current awareness and input from nurses/midwives on genomics and related pathways:
 - a) Where are the gaps where nursing/midwifery input re: diagnosis/care would be beneficial?
 - b) Are there areas of existing best practice which could be shared across the region?
- 3. Develop a strategy for workforce development and delivering genomics education and training opportunities for nursing and midwifery teams across the region.
- 4. For transformation projects focusing on nursing and midwifery clinical practice consider:
 - a) What are the GMSA priority clinical pathways to be developed and where do nurses and midwives work in these end-to-end pathways? Where would making changes to clinical practice provide the most benefits to patients? Which staff groups need to be engaged?
 - b) Which nursing/midwifery led/focussed genomics services are currently offered within the region and is there any scope for extending these to minimise variation of services/access?
 - c) Are there existing projects or research activity on nursing/midwifery genomics in clinical practice in the region and how would these link in?
 - d) Are there opportunities to develop the role of the nurse/midwife in genomic pathways?
 - e) Implementation issues for nursing and midwifery in clinical practice:
 - i) Clinical guidance, conversations with patients and families and decision support
 - ii) Information for patients and the public
 - iii) Data to measure the baseline, the interventions (skills training/education etc) required and implementation plan to test and embed into clinical practice
 - iv) Implementation across different sectors in primary and secondary care

5. How will progress be evaluated? As the priorities for the nursing and midwifery transformation programmes in GMSAs are defined, consider the metrics and data that could be used to measure progress from baseline towards final goals.

This information will be shared with colleagues leading the GMS Alliance plans in each region. To discuss local plans or share any comments and suggestions, please contact Sarah Armstrong-Klein, sarah.armstrong-klein@nhs.net; or Marie Batey m.batey@nhs.net Genomics Unit, NHS England and NHS Improvement