



The Association of Genetic Nurses & Counsellors

## **AGNC Genetic Counselling Research Policy and Strategy 2026 - 2031**

### **1. Introduction**

The National Health Service (NHS) is committed to delivering high-quality, evidence-based healthcare that drives better patient outcomes. Research and innovation play a central role in shaping the future of healthcare and ensuring that healthcare professionals continuously enhance their skills and practices. This Research and Innovation Strategy Policy aims to provide guidance and a clear framework for Genetic Counsellors within the NHS, fostering an environment that encourages engagement in research and innovative practices, contributing to advancing genetics services. This policy is aligned with the principles outlined in the AGNC Vision, Mission and Values Statement, ensuring that research activity reflects the patient centred, ethical and equitable foundations of the profession.

<https://www.agnc.org.uk/info-education/documents-websites/#AGNCVisionMissionandValuesStatement2023>

This policy and delivery plan cover the period from 2026 to 2031 and will be reviewed in 2029 and 2031.

### **2. Background**

This strategy is set in the context of several significant developments. These are the evolution of the genomics service, mainstreaming and the wider NHS transformation strategy.

#### **A time of change**

The provision of genetic testing in the NHS is undergoing a period of significant change. Several factors are driving these changes.

#### **2.1 Mainstreaming**

In 2018, the National Health Service (NHS) Genomic Medicine Service (GMS) was launched in England to create a step change in the use of genomics in the NHS, including offering whole genome sequencing (WGS) as part of routine care for both rare disease and cancer.

The consequence of this is that the widest ever breadth of non-genetic clinicians across the NHS can now directly offer genomic tests to patients at point of care. This is often referred to as 'mainstreaming' and test criteria, including the specialists authorised to order the test, are set out in the National Test Directory.

## **2.2 Scientific and medical advances**

The last 10 years have seen a rapid increase in sequencing speed and a substantial reduction in costs. The availability of whole exome and genome sequencing has led to clinical genetic testing moving away from single genes, instead offering testing via panels testing multiple genes at once. This development has increased the molecular diagnostic yield for inherited conditions. It has also meant that the complexity of the tests available has increased. More genetic testing, across more genes and for a wider range of clinical indications, is now available to patients in the NHS. The availability of genetic testing also means that more people than ever are accessing genetic testing outside the NHS - either in research settings or through commercial direct-to-consumer (DTC) services.

## **2.3 Evolution of genomic medicine services**

Genetic counsellors have predominantly worked with genomic medicine services. These specialist services, and their role within the NHS, are evolving.

The role of specialist clinical genetics services has historically been to facilitate diagnostic and predictive genetic testing. Their role also extended to interpreting results, helping patients in decision-making about genetic testing and supporting colleagues and patients in understanding the therapeutic and management implications of the result. Clinical genetics services also provide risk assessments – most commonly but not exclusively in the area of cancer – to help with screening and surveillance recommendations based on family histories.

A consequence of 'mainstreaming' is that the treating physician can now directly request and receive genetic information, without a referral, assessment and analysis by clinical genetics services. On the current NHS Test Directory there are very few tests that can only be ordered through clinical genetics services. As such the clinical genetics service's role as provider and 'gatekeeper' of genetic testing is vastly diminished.

We do not know how clinical genetics services will evolve in response to the changing landscape of genomic medicine. Healthcare professionals may play a more active role in the treatment and management of patients, especially in rare disease patients – complex patients whose care often requires coordination of several specialities. The profession may become increasingly focused on educating and supporting colleagues offering genetic testing within the NHS. Clinical genetics and genetic counsellors may increasingly work embedded into other specialist teams. The profession may move towards focusing on the most complex cases, either medically or to those affected psychologically by the result of a genetic test or their family history.

What we do know is that Genetic Counsellors working in clinical genetics services in the NHS will experience significant change..

While the majority of genetic counsellors in the NHS work in clinical genetics services, increasingly genetic counsellors are working in different academic and healthcare settings. Some genetic counsellors are working in the NHS but in embedded roles. This allows them to support colleagues with testing, risk assessment and genetic counselling. Other genetic counsellors are providing genetic counselling in the private sector, often supporting patients who are having direct-to-consumer genetic testing. Genetic counsellors are also increasingly working in education, training, policy and research. Finally Genetic Counsellors are also working within the charity sector supporting patients in a wide variety of situations where support may not be accessible through other routes.

## **2.4 Wider policy and political landscape**

Several significant policy and political agendas are also shaping the landscape of how genetic testing is delivered. On a very broad level, the UK Government has published a 10 year plan setting out three strategic shifts. These are:

- Hospital to community
- Analogue to digital
- Sickness to prevention

There are also more specific policies that shape the evolving landscape within the NHS. In 2022 a report was published called “Accelerating genomic medicine in the NHS.” This outlined four priority areas to be delivered from 2022-2027. These are

1. Embed genomics across the NHS, through a world-leading innovative service model from primary and community care through to specialist and tertiary care.
2. Deliver equitable genomic testing for improved outcomes in [cancer](#), rare, inherited and common diseases and in enabling [precision medicine](#) and reducing adverse drug reactions.
3. Enable genomics to be at the forefront of the data and digital revolution, ensuring genomic data can be interpreted and informed by other diagnostic and clinical data.
4. Evolve the service through cutting-edge science, research and innovation to ensure that patients can benefit from rapid implementation of advances.

Finally there is the UK government’s rare disease strategy. Published in 2021 and with a follow up action plan published in 2024, these documents outline four priority areas. These are:

1. Helping patients get a final diagnosis faster
2. Increasing awareness of rare diseases among healthcare professionals

3. Better coordination of care
4. Improved access to specialists care, treatment and drugs

Together, these scientific, professional and policy developments represent significant and interconnected change.

### 3. Purpose

To date, genetic counsellors in the UK do not have a stated research policy. This puts us at odds with other comparable healthcare professionals. Nurses and [Midwives](#) both have published research strategies. Allied Health Professionals (AHP) is an umbrella term referring to 14 different professions. These include: Occupational Therapists, radiographers, speech and language therapists, physiotherapists and dietitians. All 14 AHP associates have research strategy policies and guidance and there is an overarching [AHP strategy for research](#). Organisationally, in the NHS, genetic counsellors fall under governance of the regulatory body the Academy of Healthcare Sciences (AHCS). While the AHCS does not have a published research strategy, in their published standard for the [Healthcare Science workforce](#) research is listed as one of the key domains of Good Scientific Practice.

Research is a key component in ensuring that Genetic Counsellors are best able to meet the needs of patients and respond in an agile manner to the evolving landscape in which they find themselves. It is research that allows people to react to and also shape the landscape in which they find themselves professionally.

This policy draws a distinction between three types of research. They are interlinked but also distinct.

First, there are the ways in which Genetic Counsellors can contribute to ongoing research within the NHS. Examples include the DDD study, CanRisk, the 100k Genomes Project and many others. In this sense, Genetic Counsellors are facilitators of research

Second, there is research that focuses on the implications and implementation of genomic testing in clinical settings. This can include accessibility, equity, acceptability and psychosocial impact of genetic testing. It may also include research that is inward-looking towards the profession, exploring how genetic counselling works and the impacts it has on patients and the wider healthcare system. This, in a broad sense, contributes towards Genetic Counsellors' commitment to working within a framework of 'evidence-based medicine.'

Finally, there is wider research that explores the implications of genomics, focused on the Ethical, legal and social implications (ELSI) of advances in genetics.

This policy provides a structured framework for Genetic Counsellors to engage in, lead and influence research. It facilitates professional development of Genetic Counsellors, to meet the

needs of patients, to react flexibly to changing landscapes, to shape the 'genomic era' through the philosophy and skills of genetic counselling and to ensure that we are working within a framework of evidence-based medicine. This policy expressly views research and clinical work as symbiotic, each essential for the other.

The policy sets out the strategic direction for the involvement of Genetic Counsellors in research and innovation, both within the NHS, and beyond

#### **4. Mission**

The overarching mission of this policy is to improve GC professional practice and the genomic healthcare of patients and families through research.

The AGNC has identified four key principles necessary to deliver this mission:

- I. To support and develop research capacity amongst genetic counsellors,
- II. To promote ethical, inclusive and responsible research,
- III. To enable the translation of research into GC clinical practice,
- IV. Enhance the profession of genetic counsellors in the UK and globally to enable contribution to genomic innovation.

These principles provide a framework for the AGNC Research and Innovation Strategy (to be developed) and the work of the Research sub-group (to be established).

#### **5. Scope**

The policy applies to all Genetic Counsellors who are members of the AGNC. This includes Genetic Counsellors employed within the NHS, as well as those in training, private practice, academia, charity and the commercial sector with a focus on facilitating participation in research and innovation activities. The policy is also relevant to managers, educators, and leaders in genetics services.

#### **6. Conclusion**

The involvement of Genetic Counsellors in research and innovation is essential for the continued advancement of genetic healthcare. By fostering a culture of inquiry and improvement, this policy aims to ensure that NHS Genetic Counsellors not only keep pace with emerging scientific knowledge but also contribute to its development. The success of this strategy will ultimately lead to better outcomes for patients and a more dynamic, forward-thinking genetics workforce in the NHS.

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