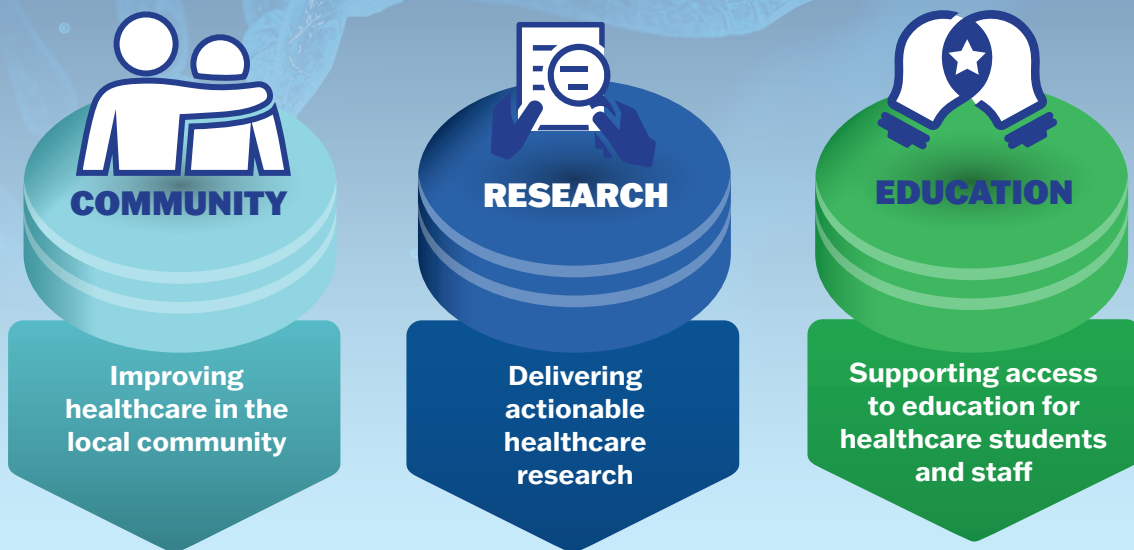




# ADELAIDE HEALTH FOUNDATION

The Adelaide Health Foundation (AHF) is a voluntary foundation focused on advancing and promoting equitable access to healthcare services and education in Ireland, through the pillars of Community, Research and Education.



**With a history of supporting and publishing evidence-based research which can influence change within the Irish healthcare system, we commissioned a research study into Genetic Testing & Genetic Counselling services in Ireland.**

Under our current strategy, we have a commitment to follow through on AHF funded research projects by **supporting the implementation of study recommendations**. This means that rather than let valuable recommendations “sit on the shelf” without responsibility, we commit to taking some action.

We welcome the research report and it’s findings by UCD Research team led by Professor Sally Ann Lynch.

Shortcomings in genetic testing and counselling services in Ireland are already well documented, and this study’s findings and recommendations confirm the need for investment and further development of genetic and genomic services to improve services for Irish patients and families.

The public should be informed to help them understand the role of Genetic Counsellors, and there is much to improve on laboratory infrastructure for genetic and genomic tests. The lack of protected status for the Genetic Counsellor role is an issue and an area in danger of exploitation as citizens are encouraged to have commercially driven genetic testing online, right up to whole exome sequencing.

**In response to the report findings, the Adelaide Health Foundation commit €1.5m to a 3-year programme to support improvements in Irish Genetic Testing & Counselling services.**



## AHF VISION

- Quality training is delivered in a subject where intellectual rigour is matched by ethical content.
- Academic leadership in the field is promoted and supported.
- Delivery of national strategy is supported.

## WHERE TO START

The Research study yielded 8 recommendations across the full spectrum of current delivery of genetic services in Ireland, which will be shared and promoted by the Adelaide Health Foundation

Through a three-year multi-phase project [2025-2027], and working in conjunction with national, academic and healthcare partners, the Adelaide Health Foundation will support projects which improve the patient experience.

Commencing with a focus on education, other initiatives will be considered. We are keen to support projects which align with AHF Mission and our Vision for improved genetic and genomic services for patients and families.

# PROGRAMME 1 – EDUCATION

The research report's recommendations are reflective of key areas of focus in the HSE and Department of Health's *National Strategy for Accelerating Genetic and Genomic Medicine in Ireland* and work is underway to implement the recommendations

Responsibility for driving the implementation of the national strategy lies with the HSE's National Genetics & Genomics Office [NGGO].

Programme 1 will be delivered in two phases and will involve development and delivery of Genetics based education to healthcare providers.

As there is a clear alignment between the AHF selected Education focused recommendation and the NGGO's Key Strategic area of focus; 'Building the genetics and genomics workforce of the future', we intend to collaborate with the NGGO on **Phase 1**.

AHF Research Study Recommendation [No. 6]	NGGO Key Strategic Area of Focus <i>Building the genetics and genomic workforce of the future</i>
To develop a national educational framework to support the growth of mainstream genetic and genomic testing	Improving the genetic and genomic literacy of the healthcare workforce
To develop health care professional competency in genomic testing and consenting procedure	Accessible information, resources, and educational and training packages will be developed for healthcare professionals, policy makers, and healthcare managers to increase genetic and genomic awareness and literacy

Programme 1 will be delivered in two phases and will involve development and delivery of Genetics based education to healthcare providers.

## Phase 1

### "Introduction to genetics" programme for Health & Social Care Professions (HSCPs)

- An accredited education programme for HSCPs.
- A pilot project will be delivered to Tallaght University Hospital HSCP staff, with content guided by NGGO, and funding/project management by the AHF.
- Following evaluation, the programme will be made available to all healthcare staff through the HSELand online education and training portal.

## Phase 2

### MSc in Genetics

In conjunction with Trinity College Dublin, the AHF will support the development of a post-graduate education offering for delivery to health professionals with a keen interest in genomic medicine.

## What next?

We expect that other initiatives will present as the project develops and opportunities which align with both AHF Mission and our Vision for improved genetic and genomic services which will improve services for patients and families.



Tallaght  
University  
Hospital

An Academic Partner of Trinity College Dublin

Ospidéal  
Ollscoile  
Thamhlachta



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

# RECOMMENDATIONS

The researchers made 8 recommendations for both Policy and Practice based on the integrated findings from all aspects of the project.

1	<b>There should be timely access to clinical genetics expertise to ensure families had an understanding of the implications of a genetic diagnosis and had access to care pathways.</b>
2	<b>Ongoing HSE support and investment for clinical genetics teams was required, to ensure the delivery of a safe and effective service, to increase current staffing levels and invest in new roles such as genomic resource associates and laboratory gatekeeping staff.</b>
3	<b>HSE and employer provision of protected time and funding for genetic counsellors was needed to access continuing professional development, and counselling supervision to maintain competency and registration</b>
4	<b>There should be formal HSE recognition of the profession to ensure Genetic Counsellor was a protected title to safeguard patients and practitioners.</b>
5	<b>A national genetic testing directory was required to support clinicians and laboratories in optimal and ethical testing and implementation of gatekeeping</b>
6	<b>A national educational framework should be developed to support the growth of mainstream genetic and genomic testing; to develop health care professional competency in genomic testing and consenting procedures.</b>
7	<b>Centralised, digitally accessible HSE laboratory infrastructure to permit genetic testing visibility and interoperability across laboratories and clinicians was urged.</b>
8	<b>A Clinical Genetics risk assessment by Clinical teams engaged in genetic and genomic testing should be used to allow accurate risk assessment and support quality improvement and patient safety</b>