Enabling access to the use, re-use, and sharing of health data for research in Ireland

Conference Report

Conference Date: Friday 28 March 2025
Venue: Royal College of Surgeons Ireland,
University of Medicine and Health Sciences,
123 Stephen's Green, Dublin.

On 28th March 2025, Professor Gianpiero Cavalleri, Royal College of Surgeons Ireland (RCSI), Professor Aisling McMahon (School of Law and Criminology, Maynooth University), Dr Ciara Staunton and Dr Laura Whelan (RCSI), organised and hosted a multi-disciplinary conference at the Royal College of Surgeons Ireland (RCSI) Dublin on "Enabling access to the use, re-use and sharing of health data for research in Ireland".

Conference Aims and Background

Timely access to the use, re-use, and sharing of health data for research is critical to improve individual and population health, ensuring better outcomes for current and future generations. Navigating such access, however, is fraught with legal, ethical, and societal complexities. These challenges are compounded given the evolving regulatory landscape, particularly with the coming into force of the European Health Data Space (EHDS), which aims to create a harmonised framework for data sharing across Europe. The EHDS will require implementation in each national Member State, including in the Irish context. Alongside the evolving legal landscape, governance frameworks for data sharing must consider and anticipate ethical, legal and societal considerations related to emerging technologies in the field, such as genomics and artificial intelligence. The potential benefits of access to health and genetic data for health research are significant but can also pose ethical, legal and societal challenges. In this dynamic environment, such challenges need to be considered and addressed through nuanced, interdisciplinary dialogue.

Against this backdrop, this conference explored how a trustworthy data sharing ecosystem for health research could look in Ireland, one that enables accessibility while mitigating risks, fostering trust, and advancing health equity. Discussions on the day probed a range of issues including: current challenges in accessing, using, and sharing genetic and health data for research purposes in Ireland; the European Health Data Space (EHDS) and its implementation in Ireland; legal and ethical considerations surrounding data access, use, and sharing with industry partners and within public-private partnerships; and avenues for enabling responsible access, use, and sharing of genetic and health data in Ireland, which included consideration of case studies and approaches in other jurisdictions.

To start the day, Prof Fergal O’Brien (Deputy Vice Chancellor for Research & Innovation, RCSI) offered an opening address and welcome to the conference attendees. Following this, Prof Gianpiero Cavalleri (RCSI) and Prof Aisling McMahon (Maynooth University) offered an introduction to the conference topic and aims, and a brief overview of the current landscape and dynamic nature of the space with reference to the evolving legal/regulatory landscape. The conference then featured three main sessions.

Session one was chaired by Dr Derick Mitchell (The Synergist) and speakers in this session considered the current genetic and health data landscape in Ireland including the current challenges & opportunities around data sharing for health research purposes. Speakers were: Prof Rachel Crowley (Co-Lead, Rare Disease Research Catalyst Consortium, Consultant Endocrinologist SVUH & Clinical Professor University College Dublin); Dr Emer Doyle (Head of Health Policy at the Department of Health, Ireland); Nuala Ryan (PPI participant); and Dr Emily Vereker (Head of National Office, National Office for Research Ethics Committees (NREC)).

Session two chaired by Dr Georgina Flood (Consultant, Mater Hospital, Dublin) explored best practice case studies for enabling access to data for health research in an ethically robust manner. Speakers were: Dr Natalie Banner (Director of Ethics, Genomics England); Prof Johanna Blom (Professor in Psychobiology and Pediatric and Behavioral Neuroscience, University of Modena and Reggio Emilia, Italy); and Dr Deborah Mascalzoni (EURAC Research, Italy and Associate Professor in Biomedical Ethics at the Centre for Research Ethics and Bioethics (CRB) at Uppsala University, Sweden).

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The final session was chaired by Prof Edward Dove (School of Law and Criminology, Maynooth University) and featured a roundtable discussion on creating a trustworthy data sharing eco-system in Ireland for impactful research. Roundtable speakers were: Dr Amy Holtby (PPI contributor); Prof Orla Hardiman (Professor of Neurology and Head of the Academic Unit of Neurology at Trinity College Dublin, and Consultant Neurologist at Beaumont Hospital); Dr David Murphy, Deputy Commissioner, Data Protection Commission; Dr. Ana Terrés (Head of Research and Evidence, Assistant National Director at Health Service Executive (HSE) Ireland); and Dr John O'Neill, Head of Research Policy and Innovation, Department of Health.

Following this, Dr Ciara Staunton offered reflections as a rapporteur on the discussions during the day. She reflected on some of the challenges around the use of health and genomic data for research in Ireland within current systems, the evolving legal framework including the EHDS, and key considerations around enabling an ethically robust effective system for access to health/genomic data for research in the evolving landscape in Ireland.

Dr Laura Whelan then closed the event with reflections on next steps and plans for a policy report arising from this event, which the organisers are currently developing, and will be published in coming months.

Funding Acknowledgment: This conference was organised by: Prof Gianpiero Cavalleri (RCSI), Prof Aisling McMahon (Maynooth University), Dr Ciara Staunton, Dr Laura Whelan (RCSI). The organisers are very grateful to the Assisted Living and Learning (ALL) Institute, Maynooth University; School of Law and Criminology, Maynooth University; Royal College of Surgeons Ireland and FutureNeuro for their support and funding in organising this conference.

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