

Theme - GDPR and Health Research: Stakeholder Voices

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Hilton Dublin, 9.00am - 1.00pm

Wednesday, 14th November 2018

FORUM AGENDA

9.00am Registration & Networking Opportunity

9.25am Welcome

Professor Brendan Buckley; Chairperson, IHRF Steering Group

9.30am **GDPR and Health Research Regulations: Setting the Scene**

Dr Suzanne Bracken; Clinical Research Development Ireland (CRDI)

9.50am **Where Ethics meets Clinical Data**

Professor Jon Fistein; Associate Professor in Clinical Informatics, University of Leeds

10.20am **Patient perspectives panel discussion**

Chair: *Dr Avril Kennan; CEO, Medical Research Charities Group*

Panellists:

- *Olive O'Connor; Creative Founder, MediStori and Healthcare Advocate*
 - *Caitriona Dunne; Head of Advocacy, Fighting Blindness*
 - *Orla Keane; Alpha-1 Patient Representative*
 - *Dr Sarah McLoughlin; Science Communication Officer, Retina International*
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11.00am Coffee break & Networking Opportunity

11:30am **Researcher perspectives panel discussion**

Chair: *Professor Brendan Buckley; Chairperson, IHRF Steering Group*

Panellists:

- *Dr Verena Murphy; Translational Research Leader, Cancer Trials Ireland*
 - *Emma Snapes; Head of Biobanking, INFANT Centre, University College Cork*
 - *Professor Gianpiero Cavalleri; Associate Professor of Human Genetics, Royal College of Surgeons in Ireland (RCSI)*
 - *Professor Alan Irvine; Professor of Dermatology, Trinity College Dublin*
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12.10am Audience Q&A

12.55pm **Key Learnings and Next Steps**

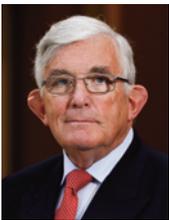
Eibhlin Mulroe; CEO, Cancer Trials Ireland

1.00pm Meeting Close



Dr Suzanne Bracken is a Translational Research Manager in Clinical Research Development Ireland (CRDI). Suzanne has worked in CRDI (formerly Molecular

Medicine Ireland) for the past 7 years; her role involves fostering collaborative translational research. She has coordinated research networks, bringing academic, clinical and industry partners together, project managed multi-institutional research projects and promoted a harmonised approach to biobanking. She currently chairs the NSAI National Biotechnology Standards Committee which was established to monitor and participate in the work of ISO/TC 276. Suzanne has over 5 years' experience in the In Vitro Diagnostics industry IVD industry. Suzanne graduated with a PhD in Immunology from Trinity College Dublin. She also holds a degree in Chemistry from UCD and a Master's degree in Biomedical Science from the University of Ulster, Coleraine.



Professor Brendan Buckley has about 40 years' experience as a physician scientist. He was Chief Medical Officer of ICON plc from 2011 until his

retirement in 2017. He has directed a number of very large outcomes trials in metabolic /cardiovascular disease and chaired independent data and safety monitoring boards for a number of large clinical development programmes, including for a number of orphan medicines. He is Honorary Clinical Professor at UCC and Adjunct Professor at UCD.

He was formerly a board member of the Irish Medicines Board (now HPRA), a member of the EMA's Committee for Orphan Medicinal Products (COMP) and EMA's Scientific Advisory Group for Diabetes and Endocrinology. Brendan has been a board member of Breakthrough Cancer Research since 2011 and is the Chairperson of Fighting Blindness.



Prof Gianpiero Cavalleri is a B.Sc. graduate of Trinity College Genetics Department. He completed a Ph.D. in human genetics at

University College London in 2006, where his work focused on haplotype mapping in epilepsy genetics and pharmacogenomics. After his Ph.D. he worked at the Institute for Genome Science and Policy at Duke University, North Carolina before joining the Royal College of Surgeons in 2006. For the past ten years he has developed a research group working at the interface of computational genetics, human evolution and clinical research. Gianpiero is Associate Professor of Human Genetics and has been faculty member at RCSI since 2008.



Caitriona Dunne is Head of Advocacy with Fighting Blindness. Her role includes an information and resource function and focuses on supporting

and facilitating patient involvement in medicines research and development processes.

Caitriona represents Fighting Blindness on the MRCG Communications and Advocacy Group, the IPPOSI Research and Advocacy Network, and the Rare Disease Taskforce. She is a patient representative on the HSE National Clinical Programme for Rare Diseases Working Group.

Caitriona has a BSc in Sport and Exercise Science from the University of Limerick and an MA in Health Promotion from the National University of Ireland, Galway. She is a graduate of the European Patients' Academy (EUPATI) training course on medicines research and development. Caitriona has been a board member of the Prader Willi Syndrome Association of Ireland since 2015.



Professor Jon Fistein originally trained as a medical doctor and barrister and has worked in health informatics for over 20

years. He has supported NHS, social care, academic, third sector and commercial organisations across a range of strategic, managerial and technical projects. Jon has particular experience in information governance. He was Head of Clinical Ethics and Data at the UK Medical Research Council and a member of the Independent Group that Advises NHS Digital on the Release of Data (IGARD). He is a Founding Fellow of the Faculty of Clinical Informatics and a Senior Fellow of the Faculty of Medical Leadership and Management.

He is currently Chief Medical Officer for the Private Healthcare Information Network (PHIN), the independent, UK government-mandated source of information about private healthcare, working to empower patients to make better-informed choices of care provider. At Cambridge University, he leads the teaching on Leadership and Management for clinical medical students and at Leeds University he is responsible for the Health Informatics teaching portfolio. His research examines the legal, professional and ethical implications of using healthcare data for uses outside the direct care setting.



Prof Alan Irvine graduated in Medicine from Queen's University Belfast (QUB) in 1991. In 1998, he was awarded a research doctorate (MD) in

Human Genetics, also from QUB. He completed Dermatology Training in Belfast in July 1999, followed by fellowships in Great Ormond Street Children's Hospital, and Children's Memorial Hospital Chicago, where he was a Fulbright Scholar.

He was appointed Consultant Dermatologist (Attending Physician) in Our Lady's Children's Hospital and St. James's Hospital, Dublin, in 2002. The OLCHC department provides specialist clinics in severe atopic dermatitis, vascular malformations, laser treatments, and genetic skin diseases with more than 10 000 secondary and tertiary paediatric attendances per annum.

He is Professor in Dermatology, Trinity College Dublin. His research interests are in epithelial genetics, disease mechanisms in, and therapy of, atopic dermatitis. He is funded by the National Children's Research

Centre and the Wellcome Trust, and has attracted approximately €11M funding to date



Orla Keane was diagnosed in 1996 with a severe form of Alpha 1 antitrypsin deficiency disease in her lungs which is a genetic condition. She found the first ten years very debilitating however that all changed when she had an opportunity to participate in blind clinical trials in 2006 which involved weekly infusions. She was officially receiving Respreeza from 2008 and with it came a notable improvement in her quality of life and a slowing down of the disease. She has participated in a conference on Ethics in St. James hospital and was invited to tell her story at the Royal College of Surgeons. Unfortunately when the drug was licensed, Orla and her fellow Alpha-1 patients found the future of drug access under threat. This forced them to rally together to form the A1 Action Group. Orla also found herself in the uncomfortable position of having to speak for the cause in the media. Their future is still uncertain.



Dr Avril Kennan has a PhD in genetics and many years subsequent lab experience working on human genetic conditions. She moved from the lab in 2007 to

become a patient advocate with DEBRA Ireland. In her role there, as Head of Research and Advocacy, she led a number of international initiatives including the development of evidence-based clinical guidelines and an international patient registry. Dr Kennan has sat on many Boards and Committees, including the DEBRA International Executive Committee and the Rare Diseases Ireland Board. In her role as CEO of the MRCG she is passionate about supporting medical research charities and promoting their role in society. She was one of the founders of the Irish Health Research Forum.



Eibhin Mulroe was appointed CEO of the Cancer Trials Ireland (formerly ICORG) in June 2015. Under her leadership, Cancer Trials Ireland rebranded, moved to a bespoke office space, commissioned an Economic Impact Report (DFK) on cancer trial activity in Ireland, worked with InterTrade Ireland in 2017/8 to revisit the all-Ireland cancer trials network and established a Patient Advocate Advisory Group.

Ms Mulroe sits on the Ehealth Ireland Committee which supports the implementation of the Irish government's Ehealth Strategy. She is a member of the Royal Irish Academy Life Sciences Committee. A member of the Governance Committee of Blood Cancer Network Ireland (BCNI). The Irish Health Research Forum appointed Ms Mulroe to their Steering Group in 2018. A member of the Advisory Board of the Cork Clinical Research Centre.



Dr. Verena Murphy is the Translational Research Leader in Cancer Trials Ireland. She has a PhD in Biochemistry from the University of Zurich,

Switzerland, and worked at a variety of academic and clinical research laboratories in Germany, Switzerland, Canada and Ireland with a focus on cancer research, in particular brain tumours.

In Nov 2009, she took up a position as Translational Research Coordinator in the strategic research cluster Molecular Therapeutics for Cancer Ireland (MTCI) directed by Prof John Crown and started working in this capacity in the All Ireland Cooperative Oncology Research Group (ICORG), today Cancer Trials Ireland. In 2015, she became Clinical Programme Leader, and in 2017 Translational Research Leader, working on the oversight and execution of operational strategies for multiple programs in the oncology portfolio.

Over the last 9 years Verena together with her team built up a substantial translational portfolio consisting of purely translational, academic studies and clinical studies with translational sub-studies.



Olive O'Connor is a family advocate and patient innovator.

Having first-hand experience of the issues

that can arise from manoeuvring within the health system, from being both a patient and carer of her four daughters; award winning social entrepreneur, Olive has a passion to drive, promote and educate all stakeholders on the importance of engagement, partnership, self-management and self-care.

She is a trained Self-Management Facilitator of Chronic Disease with Stanford University. Olive is a Fellow of ISQua for Patient Safety and Quality Improvement and was awarded a Fellowship by the England Centre for Practice Development, Canterbury University. Olive is also the Ethical Governance lead for the World Health Innovation Summit.

In 2015, Olive was commissioned by the HSE to lead out on a national externally evaluated study of a person-centred health record, namely MediStori. Olive currently partakes in extensive participatory research with patients, carers and health professionals regarding the development of projects which impact on policy and practice in healthcare.



Emma Snapes is the INFANT Centre's Biobank Manager in University College Cork.

Emma's expertise lies in managing the lifecycle of precious clinical

assets to better enable advancements in translational research, working to currently accepted best practices: ISBER, OECD and MMI guidelines. She specialises in the creation of customised work flows for biobanks that are split across continents in multi-centred studies.

Her particular areas of interest are the sustainability of biobanks and the creation of global standards in the biobanking field. Emma is the national academic representative for ISO TC 276 for WG2 Biobanking and Bioresources and a member of the Education and Training Committee of ESBB.

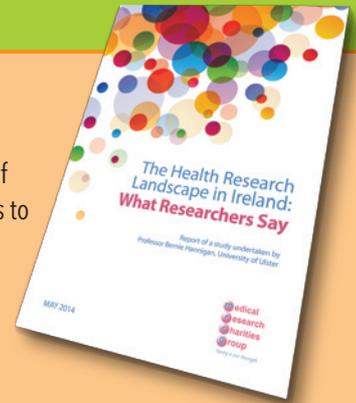
IHRF Factsheet

About the Forum

The Irish Health Research Forum (IHRF) was established by the Medical Research Charities Group on foot of their major report 'The Health Research Landscape in Ireland: What Researchers Say' in 2014. It continues to be led and managed by the MRCG and is nationally recognised for the quality and value of its events.

The Forum considers key health research issues, identifies constructive solutions and seeks consensus at twice annual Forum meetings of Health Research stakeholders with the goal of working towards the realisation of positive effects for health research, health care and ultimately the patients and public.

The IHRF Steering Group comprises of stakeholders with significant profile in health research and facilitates a coordinated approach positively influencing the health research environment in Ireland.



STEERING GROUP

The role of the Steering Group is to execute the work of the forum, to identify topics and issues for consideration and prepare for the Forum meetings.

Prof Brendan Buckley, Chairperson IHRF Steering Group.
Honorary Clinical/Adjunct Professor -UCC &UCD

Prof Eilish McAuliffe, Professor of Health Systems, School of Nursing, Midwifery and Health Systems, UCD

Dr Jacinta Kelly, Chief Executive, National Children's Research Centre

Dr Avril Kennan CEO, Medical Research Charities Group

Dr Catherine Gill, Programme Manager in Post Award and Evaluation, Health Research Board (HRB)*

Prof Roger O'Sullivan, Interim Chief Executive, Institute of Public Health

Dr Conor O'Carroll, Independent Consultant on Research and Higher Education policy and funding

Philip Watt, Chairperson, MRCG & CEO, CF Ireland

Dr Fionnuala Keane, Chief Operating Officer, Health Research Board - Clinical Research Coordination Ireland

Julie Naughton, Irish Research Staff Association

Peter Brown, Interim Director, Irish Research Council

Caitriona Dunne, Head of Advocacy, Fighting Blindness

Deirdre Hyland, Chair, Irish Research Nurses Association

Jennifer Brennan, Director of Research, Development & Innovation, THEA

Eibhlin Mulroe, Chief Executive, Cancer Trials Ireland

Dr Geraldine Canny, Head of the Irish Marie Skłodowska-Curie Office



The IHRF is a partnership of organisations and stakeholders that aims to influence health research in Ireland

*HRB have Observer status on the Steering Group.

Previous Forum Meetings

Public and Patient Involvement (PPI) in Research
4th Nov 2014

A Process to Prioritise Research Questions for Policy, Practice and Services
12th May 2015

If research is such a GOOD THING, why do we make it so HARD for researchers?
3rd Nov 2015

How can legislation facilitate health research?
10th May 2016

The Health Research Landscape in Ireland: Where are we now?
14th Nov 2017

Should Ireland set health research priorities?
21st May 2018

Documents from the Forum

The IHRF has produced valuable documents to assist our colleagues produce the best quality research possible. All are available on www.ihrf.ie

