

# Theme - The Health Research Landscape in Ireland: Where are we now?

Hilton Dublin, 9.00am - 1.00pm

Tuesday, 14th November 2017

## FORUM AGENDA

**9.00am Registration & Networking Opportunity**

**9.30am Chairpersons Welcome**

*Professor Brendan Buckley - Chairperson, Irish Health Research Forum Steering Group & Honorary Clinical/Adjunct Professor at UCC and UCD*

**9.40am Conversation: Is Patient and Public Involvement becoming the norm in Irish Health Research?**

**Chair:** *Dr Avril Kennan - CEO, MRCCG*

**Participants:**

*Dr Anne Cody - Head of Pre-Award, Research Strategy and Funding Directorate, HRB*

*Dr Derick Mitchell - CEO, IPPOSI*

*Professor Thilo Kroll - Professor of Health Systems Management, Associate Dean for Research, Innovation and Impact, UCD School of Nursing, Midwifery and Health Systems*

*Anne Marie O'Dowd - Director & Research Co-Ordinator Cystinosis Foundation Ireland*

**10.20am Ministers Address**

*Minister John Halligan, T.D.*

*Minister for Training, Skills, Innovation, Research and Development, Department of Business, Enterprise and Innovation*

**10:30am A Healthcare Legislation Update**

*Muiris O'Connor - Assistant Secretary, Research and Development and Health Analytics Division, Department of Health*

**11.00am Coffee break & Networking Opportunity.**

**11:30am Conversation: Have we made any progress on Researcher Careers?**

**Chair:** *Dr Jennifer Brennan - Director of Research, Development and Innovation, THEA*

**Participants:**

*Dr Annalisa Montesanti - Programme Manager, Health Research Careers, HRB*

*Deirdre Hyland - Director, Research Nurse Education, RCSI Clinical Research Centre & Chair, IRNN*

*Mary O'Regan - HR Research Manager, University College Cork*

**12:10pm Question and Answer Session:**

**Chair:** *Professor Brendan Buckley - Chairperson, Irish Health Research Forum Steering Group & Honorary Clinical/Adjunct Professor at UCC and UCD*

**Participants:**

*Dr Avril Kennan - CEO, MRCCG*

*Muiris O'Connor - Assistant Secretary, Research and Development and Health Analytics Division, Department of Health*

*Dr Jennifer Brennan - Director of Research, Development and Innovation, THEA*

**12.50pm Key Learnings & Next Steps**

*Philip Watt - Chairperson, MRCCG & CEO, CF Ireland*

**1.00pm Meeting Close**



**Prof. 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 has recently taken up the position of Chairperson of Fighting Blindness.



**Dr. Jennifer Brennan** is Director of Research, Development and Innovation at the Technological Higher Education Alliance (THEA). Prior to joining

THEA, Jennifer was Ireland's National Contact Point for the European Marie Skłodowska-Curie Actions (MSCA) funding programme. She represents Ireland's interests in the MSCA programme as National Delegate to the MSCA Programme Committee. Jennifer has a background in research and has worked in academia in the UK, USA and Ireland. She is particularly interested in researcher career development, gender in research, responsible research & innovation, and is the Deputy Chair of the National Forum on Research Integrity.



**Dr Anne Cody** has a background in cell biology and spent ten years as a researcher in Germany and Ireland. She has been working with the Health

Research Board in a variety of roles over the last 14 years, mostly focussing on clinical and applied biomedical research. In her current role Dr Cody is responsible for overseeing the development of integrated and synergistic funding initiatives across the HRB remit, implementing the HRB strategy and the vision of 'healthy people through excellent research and applied knowledge'. She has taken the lead in the development of the HRB's approach to Public and Patient Involvement (PPI). This was informed by a survey of researchers and a survey of members of the public, leading to a dedicated funding initiative and changes to the way the HRB works.



**Deirdre Hyland** is Director of Research Nurse Education with the RCSI's Clinical Research Centre in Beaumont Hospital. Deirdre co-ordinates the

Postgraduate Certificate in Clinical Research Nursing (through the RCSI) as well as other educational programmes, including Good Clinical Practice (GCP), throughout Ireland. Deirdre is also a member of the Education Work-stream of the UK Clinical Research Facilities Network (UKCRF).

Deirdre completed her general nurse training and midwifery in St James's Hospital and Dublin. She completed her Higher Diploma in ENT nursing in 1999 and a MSc in Nursing Practice in 2003. In 2004 Deirdre took a post as a clinical research nurse with the RCSI's Clinical Research Centre.



**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.



**Professor Thilo Kroll** is the UCD lead for the HRB funded Public and Patient Involvement initiative PPI Ignite. Since 1992, Prof Kroll has conducted research

into the social dimensions of health and well-being with a particular emphasis on public health perspectives on disability and health topics. He has carried out social and health-related research in various health systems and care environments in the United States, the United Kingdom, Germany and Scandinavia. Prof Kroll's background in psychology has led to a variety of interdisciplinary research studies combining quantitative and qualitative research methods with a particular emphasis on inclusive research designs for otherwise marginalised groups.

Prof Kroll's research interests and passion are focused on systems-related topics in global public health and inclusion. The scale of his work ranges from the individual to health and population level service systems.



**Dr Derick Mitchell** is the Chief Executive of IPPOSI - the Irish Platform for Patient Organisations, Science and Industry. He has over ten years'

experience of working in patient/public engagement, scientific communications, multi-stakeholder management and advocacy at both the national and European level. From 2011-2015, Dr Mitchell was Communications Manager of the EU Joint Programme - Neurodegenerative Disease Research (JPND).

Dr Mitchell leads IPPOSI's participation in EUPATI - a unique initiative to develop an EU-wide Patient Training Academy. He is also a board member of the Health Informatics Society of Ireland, the eHealth Ireland

committee, the Medical and Life Sciences Committee of the Royal Irish Academy as well as the oversight group on implementation of the National Rare Disease Plan for Ireland.



**Dr Annalisa Montesanti** is Programme Manager of the Health Research Careers at the Health Research Board (HRB).

The HRB is a statutory agency under the aegis of the Department of Health with responsibility for supporting and funding health research, information and evidence. She is responsible for developing and managing a portfolio of training and career development initiatives through a number of mechanisms and at many different levels – ranging from PhD training to leadership in health research and other training initiatives - and generally develop a coordinated approach to building capacity in health research in Ireland. She is also leading and coordinating several activities aimed to increase awareness and training in research data management and open science. She was educated in the Universities of Palermo and Oxford, has many years of research experience and has been working with the Health Research Board in various capacities since 2005.



**Muiris O'Connor** is Head of R&D and Health Analytics in the Department of Health. This is a new division established in late 2015 which brings together a

range of functions including ICT, eHealth, health information, research, analytics as well as international relations and engagement with academia and enterprise. The new division reflects the Department's commitment to evidence-based policy and practice and it is focussed on the management of research and innovation for the explicit purpose of achieving improved service and organisational outcomes. Prior to joining the Department of Health, Mr O'Connor worked in the Higher Education Authority (HEA), the Department of Education and Skills, the Conference of Religious of Ireland (CORI), the Economic

and Social Research Institute (ESRI) and the National University of Ireland, Galway (NUIG).



**Anne Marie O'Dowd** is a founding director of Cystinosis Ireland and Head of Research. Cystinosis Ireland was set up in 2003 to raise money to fund research,

to raise awareness of Cystinosis and to support those living with the condition and their families. It immediately set about becoming involved in Cystinosis research in Ireland and internationally and has taken part in the MRCG/HRB over the last number of years. Each year, Cystinosis Ireland runs the Dublin Scientific Cystinosis Workshop, now in its 4th year, inviting Irish and international scientists who work in the field and also those who not working in Cystinosis to encourage collaboration and continued research. Cystinosis is an ultra-rare disease with only 16 people living with it in Ireland which makes fundraising and running the charity a challenge. However, even with those challenges, Cystinosis Ireland is one of the top funders of Cystinosis research in the world and members play an active role in the Cystinosis world both in relation to science and advocacy for rare-disease generally. Anne Marie represents the charity nationally and internationally. She is the mother of 16 year old boy with Cystinosis.

[www.cystinosis.ie](http://www.cystinosis.ie)



**Mary O'Regan** is the HR Research Manager in University College Cork. Mary has a strong background in research administration from her roles in UCC and within

the Tyndall National Institute. She knows and understands the research landscape and has worked with researchers on the ground for many years supporting all aspects of their work. Mary is the designated HR point of contact for research staff within University College Cork.

Mary has a Masters in Government - Research Policy, (2014) University College Cork, Post Graduate Diploma Computer Science University College Cork and BA

(Hons) English and Archaeology also from University College Cork. She completed a Diploma in Paralegal Studies, Philadelphia Institute for Legal Studies – USA when she worked as a paralegal in Elf Atochem North America - Philadelphia USA.



**Philip Watt** is chairperson of the Medical Research Charities Group (MRCG). MRCG is at the forefront of promoting medical research in

Ireland from a patient perspective. MRCG established and supports the Irish Health Research Forum. Philip has been CEO of Cystic Fibrosis Ireland since 2009 and has worked to overhaul CF services in Ireland and to promote access to new and innovative therapies.

Philip is currently chairperson of the Irish Donor Network (IDN) which has been active in advocating for higher donor and transplant rates and in changing the organ donor consent approach in Ireland. He is also Chair of the Rare Disease Taskforce and is author of a wide range of books and articles on social policy, poverty and equality issues. Originally from Belfast, Philip is a graduate of TCD and the University of Ulster and is the author of the Irish Government's National Action Plan against Racism (2005-2008), he was coordinator of the national focal point in Ireland for the EU Fundamental Rights Agency based in Vienna (2008) and was CEO of the National Consultative Committee on Racism and Interculturalism (NCCRI) from 1998 to 2007.

# IHRF Factsheet

## About the Forum

The Irish Health Research Forum (IHRF) was established by the Medical Research Charities Group (MRCG) in 2014, on foot of their major report "The Health Research Landscape in Ireland: What Researchers Say". The IHRF is a partnership of organisations and stakeholders that aims to influence health research in Ireland and allows these bodies to work together to enable high quality research, to support research careers and to promote the involvement of service users. The Forum considers key health research issues, identifies constructive solutions and seeks consensus at twice annual Forum meetings of health research stakeholders.



### 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 Mairéad O'Driscoll**, Interim Chief Executive and Director of Research Strategy and Funding, Health Research Board\*

**Dr Helen McAvoy**, Director of Policy, Institute of Public Health  
**Conor O'Carroll**, Consultant

**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

**Harriet Doig**, Information, Research and Advocacy Officer, MS Ireland

**Deirdre Hyland**, Chair, Irish Research Nurses Association

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

\*HRB have Observer status on the Steering Group.



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## Previous Forum Meetings

### Public and Patient Involvement (PPI) in Research

4th November 2014

PPI ensures the active involvement of the public in all forms of research by bringing together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

### Process to Prioritise Research Questions for Policy, Practice and Services

12th May 2015

The purpose of research prioritisation is to make the most efficient use of limited resources in order to meet organisational, national and international objectives and ensure that patients, service users and the wider economy benefit from research efforts.

### If research is such a GOOD THING, why do we make it so HARD for researchers?

3rd November 2015

The purpose of this Forum was to lay out the career challenges facing researchers in the clinical and academic environment. It was attended by a wide range of key health research stakeholders, from researchers to funders, academic and health institutions, health charities and policymakers.

### How can legislation facilitate health research?

10th May 2016

The impetus for this Forum was the implementation of the EU Regulations on Clinical Trials (EUCT) and Data Protection (EUDP) in 2016 as well as the forthcoming Bill on Health Information and Patient Safety (HIPS).

## Documents from the Forum

The IHRF has produced valuable documents to assist our followers produce the best quality research possible. All are available on [www.ihrf.ie](http://www.ihrf.ie)

