

# Theme - 'Should Ireland set health research priorities?'

Hilton Dublin, 9.00am - 1.00pm

Monday, 21st May 2018

## FORUM AGENDA

**9.00am** Registration & Networking Opportunity

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**9.30am** Welcome

*Dr Avril Kennan, CEO, Medical Research Charities Group (MRCG)*

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**9.40am** Opening Address

*Professor Brendan Buckley, Chair, Irish Health Research Forum*

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**9.50am** Preliminary results from a Health Research Classification System (HRCS) analysis of Irish health research investment

*Dr Maura Hiney, Head of Post-Award and Evaluation, Health Research Board (HRB)*

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**10.10am** The UK perspective on health research prioritisation

*Dr Matt Westmore, Operations Director, National Institute for Health Research - Evaluation, Trials and Studies Coordinating Centre, UK*

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**10.40am** An overview of the Dutch National Research Agenda

*Professor Pancras Hogendoorn, The Netherlands Federation of University Medical Centres (NFU)*

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**11.10am** Coffee break & Networking Opportunity

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**11:40am** Conversation: The pros and cons of prioritisation

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

**Participants:**

- *Dr Patricia Clarke - Programme Manager for Policy and EU Funding, Health Research Board*
  - *Professor Nicholas Canny - Member of the Scientific Council of the ERC, 2011-16*
  - *Professor Louise Gallagher - Chair, Child and Psychiatry, Trinity College Dublin*
  - *Dr Jacinta Kelly - Chief Executive, National Children Research Centre*
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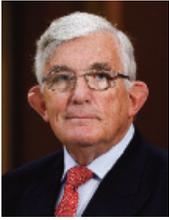
**12.50pm** Key Learnings & Next Steps

*Philip Watt, Chairperson MRCG and CEO, CF Ireland*

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**1.00pm** Meeting Close

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



**Professor Nicholas Canny** is an active publishing historian who served as Vice President for Research at National University of Ireland, Galway 2005-

2008 and was then elected to be President of the Royal Irish Academy 2008-2011. He was chosen to be a member of the Scientific Council of the European Research Council 2011-2016.



**Dr Conor O'Carroll** is an expert in the development of higher education policy, research funding strategies and proposal development. He is

also an expert in Peer Review and active evaluator for a number of national and international organisations including the Irish Research Council, Health Research Board and European Commission (Horizon 2020). Conor was the Irish Delegate to the European Steering Group on Human Resources and Mobility (SGHRM) that drives

European policy on Researcher Career Development and Mobility (2007 - 2017) and Chair from 2012-2017.

He has also led the InterTradeIreland Competitive Partnerships in Horizon 2020 programme to foster greater North/South research and innovation collaboration (2015-2017) and led the development and delivery of European policy; for example, the Principles of Innovative Doctoral Training, broadening employment opportunities for PhD graduates, now embedded in European Higher Education policy and the Horizon 2020 funding programme.



**Dr Patricia Clarke** is the National Delegate for EU Horizon 2020 Societal Challenge Health, Demographic Change and Wellbeing. Her participation in the

Horizon 2020 Programme Committee involves integrating Irish interests into EU consultations, contributing to shaping content priorities in the relevant Work Programmes, feeding expertise gained into Irish discussions, working with National Delegates from other Member States to agree joint interests or joint actions, and maintaining informal contacts with EU officials. As Programme Manager for Policy and for EU Funding she leads the HRB approach on participation in EU cofunded public-public partnerships in health research.

She is a graduate from Queens University Belfast and the University of Birmingham UK where she completed her doctorate in health behaviour change and also holds an MSc in Computer Applications. She has a long-standing interest in policy and research having previously worked in the NHS in London and with the Centre for Cross Border Studies, a UK-Ireland cross-border policy research centre.



**Professor Louise Gallagher** (MB MRCPsych PhD) is Chair in Child and Adolescent Psychiatry Trinity College Dublin and a Consultant Child and Adolescent Psychiatrist in the HSE/ National

Children's Hospital, Tallaght. She completed her medical training in University College Dublin in 1994 and trained in Psychiatry in the Dublin University Training Scheme at St. Patrick's and St. James's Hospital. Following the award of a Wellcome Trust Mental Health Training Fellowship, she completed her PhD on autism genetics in the Department of Psychiatry, Trinity College and subsequently completed Higher Specialist Training in Child and Adolescent Psychiatry.

During the course of her PhD she established a research group in Autism Genetics and this group is actively involved in the investigation of genetic vulnerability factors contributing to autism. The group is part of a large international collaboration of autism researchers, the Autism Genome Project (AGP) and Prof. Gallagher is one of the Senior Investigators of this research program. She is the principal investigator of The Autism Simplex Collection (TASC), which is an international collaborative effort to establish a repository of autism trios in association with Autism Speaks, AGRE and the NIMH. Prof. Gallagher has a busy clinical practice involving an autism spectrum disorders pre-school assessment service in the National Children's Hospital and a community based Child and Adolescent Mental Health Service in Clondalkin.



**Dr Maura Hiney** has a PhD in Molecular Diagnostics and Epizootology from the National University of Ireland Galway. She is currently Head of Post-

Award and Evaluation with the Health Research Board, Ireland. From 1990-1999 she worked as a senior researcher and managed a disease diagnostics service for the Irish fisheries industry and from 2000-2007 Maura was Head of Research Support Services for NUI Galway. She has been influential in raising awareness of research integrity (RI) issues in Ireland since 2007 and was instrumental in establishing a National RI Forum of key stakeholders and developing a national RI framework for broad adoption. Internationally, Maura chaired a Working Group of ESF Forum on RI, is a member of the European Network of RI Offices (ENRIO) and chaired the Science Europe Working Group on RI. She was a key

contributor to the European Competitiveness Council conclusions on RI in 2015. With ALLEA she coordinated a revision of the European Code of Conduct on RI, which was launched by Commissioner Moedas in March 2017. She sits on the Oversight Board of the EU-funded PRINTEGER, VIRT<sup>2</sup>UE and ENTIRE projects on research climate.



**Dr Pancras Hogendoorn** is Professor of Pathology at Leiden University, The Netherlands, and a senior pathology consultant at the Leiden

University Medical Center. Currently Dr. Hogendoorn serves as Member and Dean in the Executive Board of the Leiden University Medical Center in Leiden, The Netherlands. He completed his Medical and PhD studies at Leiden University followed by his residency in anatomic pathology. He completed fellowships in oncological pathology at the Dutch Cancer Institute, Amsterdam and Memorial Sloan Kettering Cancer Center, New York.

For the last 25 years, his scientific research has focused on the pathogenesis, morphology and molecular pathology of bone - and soft tissue tumours, resulting in over 400 original publications, several review articles and 23 book chapters. He has organised and given several national and international pathology courses over the past 15 years in 5 continents. He served as overall Editor of the 2012 edition of the World Health Organisation on classification of tumours of soft tissue and bone. He received a membership of honour in recognition of his repeated courses on pathology of bone tumours from the Belgium Society of Pathology, the European Oswald Vander Vekenprijs (2008), as well as the Corrine Farrel Award (International Skeletal Society) twice (1994 & 1998), and the Jeremy Jass prize for research excellence in 2011 and 2016, as well as prizes for postgraduate teaching. He holds a prestigious chair as visiting professor at the University of Oxford and the University of Brussel. He was coordinator of a European Community Grant application on behalf of 21 European institutes aiming at the formation of a European Network of Excellence in pathology and genetics of bone tumours ([www.EuroBoNet.eu](http://www.EuroBoNet.eu)).

Currently he is member in the steering committee of the Dutch Research Agenda ('Nationale Wetenschapsagenda') on behalf the Dutch Academic Health Centers (AHC). Furthermore, in 2015-2016 he served as co-chair in the committee which formulated the National Plan for Sustainable Health, focussing on the research and educational agenda for the Dutch AHC's.



**Dr Jacinta Kelly** was appointed as Chief Executive of the NCRC in June 2015. Jacinta has a BA (Mod) and a PhD in Immunology from TCD, and an MA in Management. She joined the NCRC in 2009 as Deputy Director of Research and has had a role in the strategic development and management of the Centre since then. She has extensive experience in third level education and research. She also has international experience in scientific publishing and communication with Elsevier and with Hogrefe and Huber Publishers. She is currently a Board Member of the Medical Research Charities Group; a member of the steering group of the Irish Health Research Forum, and a member of the ethics committee of the Faculty of Health Science, TCD.



**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.



**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.



**Dr Matthew Westmore** is the Operations Director for the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC - [www.nihr.ac.uk](http://www.nihr.ac.uk)). The

NIHR's approach is underpinned by the AViR Framework. Matt leads a cross-NIHR programme of work aimed at maximising the impact of research, reducing waste and Adding Value in Research (AViR). Matt is also a co-convenor of an international forum of funders who are interested in sharing best practice, entitled Ensuring Value in Research (EViR).

# 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 patients. The Forum considers key health research issues, identifies constructive solutions and seeks consensus at twice annual Forum meetings of health research stakeholder. The IHRF is funded and managed by the Medical Research Charities Group.



### 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 Mairead O'Driscoll**, Director Research Strategy and Funding, Health Research Board\*

**Dr Helen McAvoy**, Director of Policy, 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

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

**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

\*HRB have Observer status on the Steering Group.



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

## 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.

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

12th May 2015

This Forum meeting focused on how to prioritise research questions and sought opinion from the HRB, Patient Groups and international guests.

### 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.

### How can legislation facilitate health research?

10th May 2016

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

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

14th November 2017

This Forum revisited the topics from previous events, taking stock of the current landscape in relation to legislation relevant to health research, researcher careers and public and patient involvement (PPI).

## 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](http://www.ihrf.ie)



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