IRISH HEALTH RESEARCH FORUM MEETING

THEME: SHOULD IRELAND SET HEALTH RESEARCH PRIORITIES?

Report

Monday, 21st May 2018 – Hilton Dublin
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## Acknowledgements

We wish to thank the IHRF Steering Group, particularly the Steering Group Chairperson, Professor Brendan Buckley and MRCG CEO, Dr Avril Kennan for their input into this event. We further wish to thank all the presenters, contributors and attendees at the meeting as well as those who assisted with event registration and social media. This report was compiled by meeting rapporteur, Claire O’Connell and MRCG Events and Communications Coordinator, Linda McGrath

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Welcome

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

Dr Avril Kennan opened the event by welcoming delegates to the meeting and emphasising the importance of having a forum where leaders in health research can come together and discuss key challenges, influence policy and change things for the better in health research. She stated that the Medical Research Charities Group (MRCG) are delighted to manage the Irish Health Research Forum because it aligns with the mission of the organisation and ensures that the voice of medical research charities and patient organisations are kept central to discussions and debate.

Dr Kennan asked delegates to use an online voting platform to answer the question ‘Should Ireland set priorities for health research. In response, 33% of respondents selected ‘Yes, for all funding’ and 63% selected ‘Yes, but only for some of the funding’ (3% selected ‘No, not at all and a further 3% indicated that they did not know).

Responses to an open-text, audience question (using Slido.com) asking on what basis health research priorities should be set. The larger the text, the more times the phrase was mentioned.
Opening Address

Professor Brendan Buckley
Chairperson, Irish Health Research Forum

Professor Brendan Buckley said that Ireland has a very high quality of health research, but that what we spend on health research as a nation is relatively small compared to the research budgets of top multinational pharmaceutical companies and therefore we need to figure out our place in the ecosystem of bringing knowledge forward.

Targeting funding for prioritised areas is a way of using our finite resources smartly on areas of importance, noted Professor Buckley, who stated that one area in need of more research is the socioeconomic impact of disease on individuals.

However, putting funding into prioritised areas can also discourage the growth of green shoots and serendipitous findings in other, non-prioritised areas of research, he added, and the answer may not be confining all of the health funding in prioritised areas.
Dr Maura Hiney presented some preliminary findings from the HRB’s analysis of health research investment in Ireland between 2010 and 2015, using the Health Research Classification System.

The preliminary findings show that the HRB is a major funder of health research in Ireland, with Science Foundation Ireland and Enterprise Ireland also funding substantially in health research. Just under one-third of projects studied benefitted from co-funding through industry, the European Union, charities and other Irish agencies.

Generic health relevant funding is the largest segment for investment as this includes capital investments such as research centres and facilities. Key areas for the investment were the aetiology of disease, or how it arises, as well as treatments and interventions. Cancer research received a substantial portion of available funding, but Dr Hiney warned against designing a prioritisation strategy around individual diseases.

“There was some impact on research investment during the height of the recession, but it has subsequently recovered considerably, which is great to see.”

Dr Maura Hiney
The UK Perspective on health research prioritisation

Dr Matt Westmore
Operations Director with the National Institute for Health Research – Evaluation, Trials and Studies Coordinating Centre, UK

Dr Matt Westmore spoke about the complexity and difficulty of health research prioritisation, which focuses finite resources on areas for maximum outcome and impact.

He spoke about the need to balance prioritisation so that research communities are not stifled and to ensure that they have time to build capacity in prioritised areas so they can respond to calls. A small amount of money early on could help research groups to develop that capacity and avail of larger funding later.

Dr Westmore talked about setting short-, medium- and long-term strategies and ensuring that the appropriate research questions are being asked which will help patients.

It may be necessary to think beyond the obvious for prioritisation, he added; such as building up underlying methodology for trials processes and recruitment in order to maximise the impact of research.

“If we put out a lot of specific calls, we see a dip in uptake. The biggest challenge is trying to encourage research in areas where the research community is not well placed to respond.”

Dr Matt Westmore
An overview of the Dutch National Research Agenda

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

Professor Pancras Hogendoorn spoke about a recent Dutch initiative to engage the public in keeping health sustainable and balancing investments with outcomes.

It involved the Dutch science agenda being based on questions posed by the general public through a website. The scientific questions needed to be new and reasonably expected to be solved in 10 years.

Media helped to publicise the initiative and there was even a talk from scientists at a music and performing arts festival in The Netherlands to encourage people to think about scientific research and appreciate that it was not just for the lab. Almost 12,000 questions were submitted within six weeks, and they were whittled down.
Three major themes emerged: regenerative, prevention and personalised medicine. Members of the public could track on a website which scientists across eight institutions in The Netherlands had been funded to work on their question.

Professor Hogendoorn spoke of the need to keep health research aligned with public needs, to address unmet medical requirements and to define the societal impact of the research. He also stressed that it is important for academic health researchers to work with industry and to highlight the economic benefits of carrying out health research, including providing employment for the researchers.

“When you spend so much money on research you need to engage the public, otherwise you will lose them. We designed routes through the research landscape - scientists and ordinary people were together in drafting these game changers.”

Professor Pancras Hogendoorn
Conversation:
The Pros and Cons of Prioritisation

CHAIRED BY:

Dr Conor O’Carroll
An Independent Consultant on Research and Higher Education policy and funding.

PANEL MEMBERS:

Dr Patricia Clarke
Programme Manager for Policy and EU Funding with the Health Research Board

Professor Nicholas Canny
who was a Member of the Scientific Council of the European Research Council between 2011 and 2016

Professor Louise Gallagher
Chair of Child and Adolescent Psychiatry at Trinity College Dublin

Dr Jacinta Kelly
Chief Executive of the National Children’s Research Centre
Professor Canny said there was no getting away from prioritisation, and that even if you consider funding bodies like the European Research Council, where excellence is the only criterion, the prioritisation at national and EU level will shape the areas where excellence is developed.

Dr Clarke pointed out that the European Commission is good at putting a structure on research even without you realising it. She did not expect many changes for prioritisation between the current Horizon 2020 framework in Europe and the upcoming Framework Programme 9. However, there will be more emphasis on getting members of the public engaged in designing the calls.

Professor Gallagher stressed the importance of Patient and Public Involvement in research so that outcomes align better with what patients need. But she pointed out the risk of some people being heard more than others, and that some groups may remain more vulnerable and cut off from access, such as children and people with mental health issues and disabilities. Professor Gallagher also spoke about the importance of positioning ourselves strategically for the ‘tsunami’ of new technologies in genomic medicine that could influence understanding and treatment of rare disorders.

Dr Kelly added to Professor Gallagher’s point that he who shouts loudest may get funded, and she spoke about the importance of research on conditions in childhood and on the impact of disease. She pointed out that if you alter a chronic disease in early life, you alter an entire life course and lessen disruption on families.

She also noted the disruptive nature of the start-stop funding process, which means that research groups can lose well trained people.
Professor Canny suggested conducting a more granular exercise in the health sector to find out where we are high achieving and the areas that are being neglected. He also stressed the need for funding to go into the underlying sciences that enable these areas.

Dr Clarke spoke about the emergence of open science and the need for funders to be involved in changing how we measure the outcomes and impacts, and to engage in wider discussions.

Professor Gallagher said that we have to be sure there are equitable evaluations across all disease areas. She welcomed the democratisation of engagement in The Netherlands as outlined by Professor Hogendoorn and said we [in Ireland] need to think about something that is transparent and engages people.

Dr Kelly noted that there is a real need to collectively strike a balance between building capacity in health research and keeping avenues open.
“A publication is an output [not an impact], it might or might not get an impact down the line.”

“You may not be the person delivering the impact, and if you don’t deliver it forward, it falls, maybe through not protecting a discovery so it can’t be commercialised. We talk about interdisciplinarity, but it is a difficult thing to do.”

“We talk about research priorities, we talk about it from the academic and clinical settings, why don’t we focus on the outcomes? Why aren’t the funders saying this is the outcome we are trying to achieve, come up with ways?”

“How do we consider national policies and identify knowledge gaps?”

“It is astonishing that so much research is there, none of it has directly benefited us [families and patients with rare disease] - I don’t know how to write a grant, and the refusals are disheartening when you are trying to help families.”
“We need the public to be more ready to engage; we need open science to move faster; we need research to become the norm in the health services.”

“Has there been a detailed analysis of the effectiveness of research prioritisation in Ireland, positive versus negative?”

“Being a researcher is an inherently unstable career choice at the minute - we could find ourselves with no succession planning, no-one to hand the baton to.”

“The HRB have calls for PPI in all research by 2020, but where are the patients coming from, how are they getting involved? They may be sick people, they may not have a lot of time and money to be involved. We need a bit more thought about how to get patients involved.”
Key learnings and next steps

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

The purpose of the morning has been to ask if Ireland should engage in health prioritisation, and the general consensus is that we should, but there were some discordant voices, said Mr Watt. Balance is really important, and we need to allow for space for non-prioritised areas to emerge.

In prioritising, stakeholders need to be involved, we need to ensure that creativity is not stifled and there is a need to balance fundamental and applied research.

Priorities should not be focused on specific diseases and there needs to be allowance for ‘less obvious’ research to be funded.

The changing contexts of new medications, new policies, more research being done on previously excluded groups and how to translate into policy outcomes, pose a major challenge, he added, as does the need for new tools and modes of evaluation.

“There have been mixed results from prioritisation in the past. We need a more coherent research strategy in the future; how it is done is really important.”

Visit [www.ihrf.ie](http://www.ihrf.ie) to view presentations, images and documents from 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.

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 BUCD  
**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*  
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**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 Sklodowska-Curie Office  

*HRB have Observer status on the Steering Group.

**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 Trials (ECU) and Data Protection (EIDP) 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