

# The Health Research Landscape in Ireland: What Researchers Say

Report of a study undertaken by **Professor Bernie Hannigan, University of Ulster**

MAY 2014

**Background:** This was a study commissioned by the Medical Research Charities Group (MRCG) to understand better Ireland's current health research funding landscape from the perspective of researchers. The report was prepared by Professor Bernie Hannigan, University of Ulster.

**Objectives:**

- To determine the enablers, gaps or barriers to achieving beneficial research outcomes for patients and the population.
- To make recommendations to the MRCG and its member charities.
- To recommend to MRCG key messages to include in its advocacy work.
- To highlight for the wider research (funding) community potentially beneficial actions.



## Summary of Report

Ireland has sustained its strong support for research throughout the economic crisis. Direct interaction with clinical and university-based researchers, an online survey, stakeholder interviews and a conference revealed the co-existence of many features that enable excellent health research and a number of barriers that prevent the realisation of outcomes for health policy or services, health and wellbeing of the population or for businesses.

Recurring themes cited by study participants concerned five aspects of health research. These were:

- **Enabling Infrastructure:** Progress has been made towards putting in place infrastructure to enable health research however gaps remain and financial sustainability is a concern. According to online survey respondents the primary infrastructure elements that impact negatively on their research are; lack of a relevant patient registry; challenges relating to ethics committees; challenges relating to clinical trial infrastructure; lack of a relevant biobank; lack of legislation to govern the use of patient data; lack of

legislation to govern the use of human tissue.

- **Doing Research:** Health research funders are selectively funding particular areas of research. Research that is likely to deliver commercial outcomes or that is directly relevant to health services is the most likely to achieve funding.
- **Research Careers:** Support is focused on the earliest stages of research training (for PhD and early post-doctoral) and on established researchers. At other career stages there are disincentives to remaining within Irish health research, both in academia and in clinical careers.
- **Using Research:** Engagement with potential research users is essential to achieve the benefits of research, however, within health services this is limited.
- **Patient Advocacy:** Medical research charities support contact among researchers and patients, however, the systematic involvement in research of patients or other lay people is not well developed.

## Findings on the current research landscape:

Significant funding has been sustained however:

- There are gaps in enabling infrastructure for health research and financial sustainability is a concern
- Particular important areas of research are not prioritised
- Support is focused on the earliest stages of research training and on well-established researchers

- There is limited engagement with potential users of research findings
- The systematic involvement in research of patients or other lay people is not well developed
- The contribution of medical research charities is not recognised in policy documents.

## Recommendation:

- The creation of the **Irish Health Research Forum (IHRF)**, initiated by the Medical Research Charities Group (MRCG).
- Membership of the IHRF would comprise of representatives from health research funders and policy makers, the HSE, industry, higher education and patient organisations. The inclusion of patient organisations would add a valuable dimension.
- The IHRF would keep under review a variety of issues with broad relevance to health research. Among other issues these are likely to include:
  - Patterns of research funding and funding gaps
  - Researcher career support
  - The implementation of research findings.

## The Irish Health Research Forum: A Single Voice for Research to Improve Health

The **Irish Health Research Forum: A Single Voice for Research to Improve Health**, aims to improve the health research environment in Ireland to benefit the health of the public and the care of patients. The Irish Health Research Forum will be a partnership of organisations that influence health research in Ireland and will allow these bodies to work together to enable high quality research, to support research careers and to promote the involvement of service users.

The Forum will be led by a Steering Group comprising of representatives of member organisations. The Steering Group will identify topics that the Forum will cover, with 1-2 topics covered at each Forum meeting. Indicative topics could include items identified in the MRCG Report, *The Irish Health Landscape in Ireland: What Researchers Say*, such as researchers' careers, legislation, funding. The Steering Group will also agree Terms of Reference for the Forum.

### Agenda Thursday, 1st May 2014

- 9.30am Registration, Refreshments & Networking Opportunity**
- 10.00am Welcome and Opening Remarks**  
Philip Watt, MRCG Chairman & CEO, CF Ireland.
- 10.20am Presentation on "The Health Research Landscape in Ireland: What Researchers Say"**  
Professor Bernie Hannigan, University of Ulster.
- 11.00am The Irish Health Research Forum**  
Grace Cappock, Communications & Public Affairs Manager, MRCG.
- 11.15am Update from the Health Research Board (HRB)**  
Dr. Graham Love, CEO, HRB.
- 11.30am Questions & Answer Session & Discussion**
- 12.15pm Summation**  
Enda Connolly, Former CEO HRB
- 12.30pm Close**