The Health Research Landscape in Ireland: What Researchers Say

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

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The Medical Research Charities Group (MRCG) is an umbrella group of medical research and patient support charities, which represents the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease. A core belief of the group is that today’s health research is tomorrow’s healthcare.
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The definition of **Health Research** used throughout this document is:

Research undertaken to gain knowledge of health and disease, spanning biological mechanisms, population health, disease prevention, diagnosis, treatment and care of the person (including health services).

Medical Research Charities Group wishes to thank our sponsors:

[Logo images for Novartis and Abbvie]
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I am most grateful to all who took the time to contribute to this study. This includes people who completed the online survey or provided individual comments, who checked facts or assisted with practical arrangements for meetings. I particularly appreciated the excellent advice, insight and guidance provided by our study Steering Group. Finally, to the staff of MRCG and representatives of member organisations: You were wonderful. I trust that this report will add value to your essential work.

Because research provides hope.
*(a phrase used by many health research charities worldwide)*

Professor Bernie Hannigan, March 2014
Foreword

This report seeks to provide a snapshot of the evolving health research landscape in Ireland, at a time of considerable change and challenge. The report seeks to reflect the views of a wide range of key stakeholders including patient groups, funders, policy makers, academics and industry, with a particular emphasis on capturing the views of ‘frontline’ health researchers in Ireland.

The Medical Research Charities Group (MRCG), which commissioned this report, brings together 36 patient groups and research charities (see Annex One). We hope through this report and the research forum proposed in its conclusions, we will succeed in creating a ‘space’ for an open and constructive discussion on the health research environment in Ireland. The report aims to be strategic, forward looking and constructive, without glossing over the very real challenges for funding and sustaining health research in Ireland in a difficult economic environment. Reading this report it is clear that the current economic challenges have not only impacted on funding for health research, but perhaps more crucially, have slowed the development of an effective policy framework to underpin health research in Ireland.

For example, key pieces of policy and support vital to a vibrant health research environment such as the Health Information Bill; the Human Tissue Bill and the emergence of a unique patient identifier have still to see the light of day. A further example identified in this report is the undervaluing (and concomitant underfunding) of patient registries both in the context of providing a building block for health research and for the design and review of health services in Ireland.

There is a continued need for the funding of basic research as well as translational research in Ireland and the need for macro research policy to reflect this theme in a stronger way than at present. The need for greater clarity in respect of career paths and the avoidance of career gaps that may result in a haemorrhaging of some of our brightest and best is also highlighted in this report.

The role of patient groups in health research needs to be given greater recognition not just from a funding perspective but also because patient group involvement from the outset can help ensure that outcomes and recommendations from health research lead to tangible and relevant patient benefit. In short, greater patient involvement in health research can make a significant contribution to shaping health policy, including the delivery of services.

As the work detailed in this report progressed and findings emerged, they were presented at meetings of a Steering Group. Chaired by the MRCG, the membership of the Steering Group included Professor John Fitzpatrick (Irish Cancer Society), Dr. Maura Hiney (Health Research Board), Dr. Eucharia Meehan (Irish Research Council), Dr. Conor O’Carroll (Irish Universities Association), Dr. Avril Kennan (MRCG Board Member and DEBRA Ireland), Grace Cappock (MRCG) and Marie Downes (MRCG). Three meetings took place and provided a forum for challenge and robust discussion of the study report to ensure its accuracy, clarity and robustness. We wish to thank everyone who contributed to the steering group meetings and helped shape this report and also acknowledge our excellent partnership with the HRB and their continued support of patient led research.
The emerging findings were further tested through their presentation at a conference in November 2013, attended by over 120 people. The outcome report from this conference is available at www.mrcg.ie.

We wish to acknowledge the outstanding contribution and insight of the author of this report, Professor Bernie Hannigan, University of Ulster. Professor Hannigan’s expertise and diplomacy throughout has been paramount to the success of this project.

We further wish to acknowledge and thank the excellent support of Grace Cappock and Marie Downes of the MRCG, without whom the report and conference would not have been possible.

This report is dedicated to all those who engage in health research in Ireland, on behalf of patients in need of improved treatments we thank you for your vital work which means so much to the people we work with.

Philip Watt, Chairman, Medical Research Charities Group (MRCG)
Summary

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<th>Findings about the current landscape</th>
<th>Recommendation</th>
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| Significant funding has been sustained however:  
  - There are gaps in the 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. | Creation of an Irish Health Research Forum (IHRF): A Single Voice for Research to Improve Health, initiated by MRCG.  
  The Forum would systematically keep under review:  
  - The profile of research receiving funding.  
  - Researcher career support.  
  - The prioritisation of research questions.  
  - Outcomes from the implementation of research findings. | A vision for Irish health research, is realised, including:  
  - Research findings are used to inform health policy, practice and services.  
  - Patients and other lay people are partners on all research projects. |

Ireland has sustained its strong support for research. 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.

- **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.

**Recommendation:** Development of an Irish Health Research Forum (IHRF), with membership comprising representatives of health research funders, the HSE, industry, higher education and patients / service users. The inclusion of charities and lay people would enable a significantly different body from anything that existed previously. Suggested roles for the IHRF include developing a vision for Irish health research, systematic analysis of current research funding and research career support, considering how research questions might be prioritised and how to include health service users and lay people as research partners.
Introduction
1.0 Introduction to the Report

This is a report on an initial study commissioned by the Medical Research Charities Group (MRCG) to understand better Ireland’s current health research landscape from the perspective of researchers.

Objectives

• To determine the enablers, gaps or barriers to achieving beneficial research outcomes for patients and the population.
• To make recommendations to 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.
Features of the Irish Health Research Landscape
2.0 Features of the Irish Health Research Landscape

The Irish Government has made, and sustained, very significant investment in Research & Development (R&D), at least over the past 15 years. This commitment is recognised by researchers and, particularly with the backdrop of severe national economic challenges, is warmly welcomed. A feature of policy in latter years has been the focusing of funding onto areas of strength with a particular expectation of providing support where the country can achieve the most convincing returns on investment. The public profile of successive policies, strategies, actions and achievements has been high both at home and abroad. While Life Sciences has been a stated priority, the concept of ‘health research’ has a number of real, distinguishing features that, for the most part, are not recognised or discussed within the overall public discourse (please refer to the definition of health research at the start of this report). Three of those features that differentiate health research from R&D more generally are:

• the diverse nature of health research funders;
• the extensive, lengthy and costly translational pathways between discovery research and application;
• the need for engagement with health service provider organisations in order to achieve health benefits from research;
• the ethical, legal and clinical governance arrangements that are essential for health research.

A fourth differentiator that has emerged strongly in many countries is the advantage that can be achieved by the direct involvement of patients, their carers and the wider public at all stages in the research process.

2.1 The Action Plan for Health Research 2009-2013

This Action Plan was prepared by the Health Research Group (HRG), an inter-departmental and inter-agency group established in 2007 by the (then) ministers for Health and Children and Enterprise, Trade and Employment, under the auspices of the inter-departmental committee for the Strategy for Science, Technology and Innovation. The Plan complemented the Health Research Board (HRB) Strategic Business Plan, 2010-2014 and set out a very laudable and appropriate purpose:

“The Action Plan has been prepared to prioritise a programme of actions that are essential to creating a health research system which supports outstanding individuals, working in world-class facilities and conducting leading-edge research focused on the needs of patients and the public. Ultimately, a strong health research culture is vital if the health service is to offer the best standards of care to patients across a range of specialities and to provide robust evidence that these standards are being achieved on an ongoing basis.”

Deliverables to be achieved by 2013 were set out in the following five Action Areas:

• Leading a National Health Research System
• Developing Research Capacity in the Health Services
• Building Academic and Enterprise Links with the Health Research Sector
• Reforming the Health Research Governance Structure
• Turning Research Outcomes into Health Benefits and Economic Gains.

The Action Plan took a holistic view of health research, recognising that most of the funding to-date provided within Ireland was for fundamental, biomedical research so an additional focus on its translation and implementation was warranted.

The timing of the Action Plan was significant with the unfolding of national economic difficulties, considerable and continuing turmoil within health service organisations and, subsequently, political change. Monitoring of progress included the publication of reports. The first report, in 2010\(^3\), stated that good progress had been made but that some actions were delayed. Particularly encouraging was the increased partnership working among the research funding organisations and across sectors, primarily the health and enterprise sectors but also including agriculture with its focus on food. Many of those partnerships persist to today.

Other important initiatives were started during that period, including progress on infrastructure elements such as clinical research facilities (CRFs), the Health Information Bill and biobanking. Some, e.g. CRFs, have come to fruition while others require further progress. Notably, progress in areas involving the HSE was behind schedule. A further implementation report was compiled and noted progress in particular with regard to biobanking.

Absent from the Action Plan, or its Implementation Report, is reference to the role played by health research charities. While the focus was on Government support, there is significant mention of industry so the lack of recognition of charities as important partners of Government is surprising.

A sub-group of HRG provided advice on research careers\(^4\). A framework was proposed in 2009 that included consideration of the EU Directive on Fixed Term Careers. The intention was to gain the buy-in of universities and research funders to the principles outlined in the framework. A comprehensive response to this report was provided by the Irish Research Staff Association (IRSA)\(^5\). The IRSA welcomed the report while indicating that it was overdue. Nonetheless this work does not appear to have reached fruition.

### 2.2 The National Research Prioritization Exercise (NRPE)

While the HRG has not been active recently, its members have continued to represent health research as part of the broader NRPE Group. The NRPE report\(^6\) was accepted by the Irish Government in 2012 as a policy that would align, until 2017, the majority of the state competitive research and innovation funding to 14 priority areas (Table 1). The priorities were identified on the basis of the existing strengths of the research and enterprise base, global markets, likelihood of economic impact, jobs creation and whether a case could be made for continuing public support of the

\(^3\)www.irsa.ie/documents/HERG%20response1-1.pdf
Implementation has been driven by the Prioritisation Action Group (PAG), under the chairmanship of the Minister for Research and Innovation. In June 2013 action plans for the 14 priority areas and a monitoring framework were published. Importantly, where an Action Plan target is not achieved, its underpinning metrics should enable diagnosis of the failure in the system, leading to remedial action.

Table 1 The National Research Priorities

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<th>A</th>
<th>Future Networks &amp; Communications</th>
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<th>Food for Health</th>
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<td>B</td>
<td>Data Analytics, Management, Security &amp; Privacy</td>
<td>I</td>
<td>Sustainable Food Production &amp; Processing</td>
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<tr>
<td>C</td>
<td>Digital Platforms, Content &amp; Applications</td>
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<td>Marine Renewable Energy</td>
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<td>D</td>
<td>Connected Health &amp; Independent Living</td>
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<td>Smart Grids &amp; Smart Cities</td>
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<td>Medical Devices</td>
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<td>Manufacturing Competitiveness</td>
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<td>Diagnostics</td>
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<td>Processing Technologies &amp; Novel Materials</td>
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<td>G</td>
<td>Therapeutics – Synthesis, Formulation, Processing &amp; Drug Delivery</td>
<td>N</td>
<td>Innovation in Services &amp; Business Processes</td>
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While none of the 14 priorities relates directly to health research (as defined in this report), a commitment to support of relevant research is indicated as:

- ‘Specific integrated infrastructure’ such as clinical research infrastructure, data repositories
- Evidence-based policy research (using a minority of the competitive funding)
- And ‘Research for Knowledge’. This latter commitment would also support the development of human capital – postgraduate and post-doctoral training and the attraction and retention of world-class researchers though, without a dedicated budget line, this was expected only to utilize a small proportion of available funds.

The report also recognised that the 14 priorities were underpinned by ‘science and technology platforms’ that included basic biomedical research. It was envisaged that funding for the platform areas would be possible provided that the link between the project in question and the priorities was made clear. At this time, it is unclear the extent to which this has influenced research funding decisions.

As to the omission of research to improve health or healthcare as a specific named priority, that is generally credited to two matters. One is the focus on the existing enterprise base. Innovation-led major businesses in the health sector are located in Ireland but few undertake R&D here. The second is the NRPE’s drive for economic impact, typically within 5 years. Again, the health research charities are not a focus of the report.
2.3 The principal health research funders.

For many aspects of R&D, the predominant funder is Government, e.g. Enterprise Ireland, or Science Foundation Ireland (SFI), in addition to funds leveraged from businesses and from relevant funders internationally, especially the EU's R&D programmes. Health research funding is less likely to be provided by businesses or funders focusing on economic return - though that is not negligible - and brings into play an additional Government funder: the Health Research Board (HRB). The HRB is overseen by the Department of Health (DoH). Outside of Government and of central relevance to this report is the funding provided by health research charities – frequently termed medical research charities.

2.3.1 Health Research Board (HRB)

The HRB supports health research across a broad spectrum of activities from applied biomedical research, through clinical research to population health sciences and health services research. The funded activities draw upon a broad array of health and social sciences (laboratory sciences, management sciences, behavioural sciences, mathematics and statistics, informatics, geography etc), incorporate all clinical disciplines (medicine, dentistry, nursing & midwifery, therapies and allied health professionals) and the spectrum of diseases. Broadly speaking, funding initiatives are driven by strategic objectives in either clinical and applied biomedical sciences or population health sciences and health services research, although some funding initiatives serve both areas. Within each strategic area, the objective of a scheme may be to generate scientific knowledge through project or programmatic research, its aim may be to develop or enhance research capacity and leadership; or funding may be focused on developing enabling infrastructures, e.g. centres, networks, technology platforms, or on career development.

The HRB developed its Strategic Business Plan 2010-2014 in close consultation with the DoH and funding and development agencies in the realms of health, enterprise, education and science. Thus its strategic plan is well placed to serve the policy and evidence needs of the DoH, deliver better healthcare and services, and contribute to the wider agenda for economic development and higher education.

The HRB Strategic Business Plan 2010-2014 represented a shift away from basic research and biomedical research without a particular disease focus, and towards investment in research across three applied areas:

- Patient Oriented Research (known previously as Clinical and Translational Research)
- Population Health Sciences Research
- Health Services Research.

The objective of this realignment of HRB funding was:

- to align health research outputs and outcomes towards application in healthcare settings;
- to facilitate the development of a more efficient and effective health service;
- to expand our clinical, health services and population health research capacity;
- and to address DoH and healthcare service providers’ evidence needs for policy and practice.

The HRB’s funding schemes have been reviewed to ensure alignment with its new strategy. While the re-alignment is expected to be complete by the end of 2014, a half-way point review demonstrated considerable progress as shown in Table 2.
Table 2: Change in the % of HRB funds invested in different types of research up to the mid-point of its current strategy

<table>
<thead>
<tr>
<th>Type of research programme</th>
<th>2009 (pre-strategy)</th>
<th>2012 (mid-strategy)</th>
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<tr>
<td>Patient-oriented</td>
<td>76%</td>
<td>58%</td>
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<tr>
<td>Population Health and Health Services</td>
<td>15%</td>
<td>25%</td>
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<tr>
<td>Health Information Systems / evidence for Policy</td>
<td>6%</td>
<td>7%</td>
</tr>
<tr>
<td>Clinical Research Facilities</td>
<td>3%</td>
<td>10%</td>
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With regard to clinical research infrastructure, in 2007 the HRB made significant commitments to the establishment of CRFs in Cork, Galway and Dublin, followed in 2012 by a renewed 5-year funding package to the Irish Co-operative Clinical Research Group (iCoRG) and its statistics and data management office and for construction of the CRF at UCH Galway - originally intended to be funded by the HSE. The changes to HRB schemes already have enabled a shift in the profile of its funding allocations towards clinical research, as shown in Figure 1.

Figure 1  Changes to the HRB research funding profile at its strategy mid-point

At the same time, increased alignment with the NRPE categories has been achieved, Figure 2.
In 2012, 54% of active grants could potentially be categorised as underpinning or contributing directly to areas defined by the NRPE:

- 19% within the five priority areas relevant to health
- 35% within Research for Policy and Practice
- 27% within Integrating Infrastructure
- 10% within Research for Knowledge
- 9% within Platform Science and Technology.

HRB investment in clinical infrastructures and associated clinical activities was identified specifically in the NRPE report as being important for creating an environment within which health-relevant enterprise can develop. The biggest HRB commitments are to the CRFs, ICORG, Translational Research Awards and Clinical Scientist Awards. The latter three schemes also contribute significantly to Research for Policy and Practice.

With regard to Platform Science and Technology, just over half (57%) of the funds allocated by HRB underpins therapy development while the remainder is for research towards understanding mechanisms of disease, and thereby the potential to develop new therapeutic targets.

The HRB also builds capacity for health research through many of its schemes. In line with the organisation’s altered strategic focus, so the type of capacity building has changed. New schemes have been developed and the focus of some existing schemes has shifted. Examples include:

- Clinician Scientist Awards: An existing scheme but applicants must now demonstrate a link with health service priorities
- PhD Scholars Program – this was renewed only in the Health Services Research (HSR) area with greater focus on multidisciplinary training across a range of disciplines relevant to HSR

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Figure 2: Alignment of HRB research funding with NRPE priorities at the mid-point of its current strategy

- Research for policy & practice: 41.0%
- Diagnostics: 37.1%
- Integrating Infrastructure: 29.1%
- Platform science and technology: 26.1%
- Medical devices: 5.1%
- Therapeutics - synthesis & formulation: 5.3%
- Food for health: 2.1%
- Connected health and independent: >1.0%

% of total HRB funding commitment over period

%2010-2012
%2004-2009
• Interdisciplinary Capacity Enhancement (ICE) awards facilitate post-doctoral and more senior researchers to work across disciplines and teams

• Research Leaders Awards encourage universities to recruit senior academics in areas of relevance to the HRB strategy (HSR and Population Health)

• National Specialist Registrar (SpR) Academic Fellowships enable doctoral research by medical graduates as an integral part of their specialist training and there are plans to develop a post-doctoral scheme in 2014

• Awards through the Ireland-Northern Ireland – National Cancer Institute Cancer Consortium enable Irish researchers to access training in the US, e.g. in cancer epidemiology and health economics

• A Methodology Network is planned for 2014 to increase capacity in Ireland for research into statistics and design for complex trials

• There are plans to work with the HSE and DoH to identify innovative training initiatives within the health system for healthcare professionals

• A pilot study on Patient Safety was approved by HRB Board in 2012.

Important, especially for this report, is the joint funding scheme that HRB operates with medical research charities. The scheme is detailed below (Section 2.3.5). The HRB also collaborates with other organisations in order to leverage additional funding for researchers. These include SFI, the Department of Agriculture, Food and Fisheries, The Atlantic Philanthropies, the Wellcome Trust and the National Institutes of Health in the US. In addition, the HRB acts as the National Delegate for Health and National Contact Point for Health for the EU FP7 and Horizon 2020 programmes.

2.3.2 Science Foundation Ireland (SFI)

SFI is an agency under the Department of Jobs, Enterprise and Innovation (DJEI) and is a sister agency of the Industrial Development Authority (IDA) and Enterprise Ireland (EI). An appropriate focus at this time of austerity and high unemployment is to drive economic growth so SFI is seen by DJEI as a source of support to existing industry and to areas where new (mainly manufacturing) industry can be attracted to Ireland. Currently, there are few major employers in pharmaceutical R&D (as opposed to Manufacture or ICT etc.) and few start-ups of scale.

Life Sciences (in its broadest meaning) represents between 45 - 50% of SFI’s annual investment to-date. Considering only active awards, in 2013, the budget allocated to Life Sciences was approximately 47% and can be broken down as follows:

• Basic Biomedical Research: 19.2%
• Diagnostics: 6.3%
• Medical Devices: 1.4%
• Food for Health: 8.1%
• Agri-food: 6.3%
• Research for Knowledge: 5.4%

Overall there has been little change in the past 5 years in funding committed in each area. With the onset of the NRPE,
there is greater focus on investing in areas that are better aligned with the NRPE and areas of economic and societal importance.

Building relationships and partnerships is a key focus of SFI including with industry and the charitable sector. A new partnership scheme with other research funders was instigated in 2013 and initiatives such as joint funding with charity of major research centres may emerge, providing an opportunity to leverage SFI funding with that of larger charities or industrial partners. This would be in keeping with SFI’s development of larger centres of excellence where Ireland can compete and win internationally. The new centres include many areas of interest to the biomedical community (Annex C).

Substantial changes and improvements have been made to SFI’s career development programmes. The Starting Investigator Researcher Grant develops new young researchers towards an independent research career in any discipline. The Career Development Award, new in the 2013 call, bridges the gap between a young researcher and a mature researcher. Universities and Institutes each submit a list of candidates they wish to have considered for these awards, bearing in mind their future workforce needs (retirement profile etc) areas of specialisation / research focus etc. SFI judges the applicants on excellence and potential. In this way alignment can be achieved between future career opportunities in the Irish academic sector and the excellence / potential of researchers.

Since the majority of researchers will work in the private sector SFI also supports researchers to spend up to 12 months working in industry on a collaborative project anywhere in the world, creating links to companies who may want to invest in Ireland, building business research capacity and enabling industrial researchers to work with academics. Collaborative international schemes (e.g. with the Wellcome Trust and the US–Ireland R&D Partnership) will continue to be strongly supported by SFI for significant and excellent biomedical research.

The tri-partite collaborative funding arrangement in the US-Ireland R&D Partnership involves SFI and the HRB with funders in Northern Ireland (NI) and the US. Researchers collaborate across the three jurisdictions and submit proposals to schemes in the US run by the National Science Foundation (NSF) or National Institutes of Health (NIH). Proposals are accepted in all areas of health research and peer review is managed by the US funding organisation. Scientific excellence is the principal determinant of success.

SFI is also working with research funders in NI on collaborative research project funding to include forming strong bids to the EU’s Horizon 2020.

Leveraging the state SFI funding with other funding is a key goal including supporting researchers to win in Europe. To-date (since 2007), there have been only around 30 successful applications to the European Research Council (ERC) from Irish-based researchers. This is a low level of activity in a programme that provides excellent opportunities for fundamental research. Applications for the ERC Advanced Grant have dropped year-on-year for the past four years however applications to the early-career programmes buck this trend. SFI offers ERC development and support programmes to encourage a greater number of applications and to maximise their chances of success while other SFI career development schemes provide a feeder mechanism for future ERC applicants to the early career programmes.

Many researchers funded by SFI are also funded by HRB. Further, SFI and HRB have a collaborative partnership with the Wellcome Trust whereby, for proposals from the Republic of Ireland (ROI) that are deemed by Wellcome to be fundable, 50% of the funds are provided by SFI and HRB. There have been 785 applications for New and Senior Investigator awards since the beginning of the Partnership (2010) with 31 (4%) of those from Irish-based applicants. In the July 2013
round, 133 applications in total were made to these schemes of which 8 were from Ireland (6%). In the scheme generally, 38% of applicants progress to the interview stage, in the case of Irish applicants it is only 19%. Of those who get to the interview stage roughly half are then awarded. To-date 3 Irish applicants have been successful. SFI are encouraging and supporting more of the better established and excellent young biomedical researchers to apply to Wellcome Trust schemes.

SFI also has other collaborations with national research funders, e.g. the Translational Research scheme with HRB through which 7 awards were made; collaboration with Teagasc on ‘future agri-food’; funding for 3 policy PhDs per year for 5 years with the Higher Education Authority (HEA) / Irish Research Council (IRC); Technology Innovation Development Awards (TIDA) with EI to help translate excellent research into potential start-up businesses or licenses to existing businesses.

2.3.3 EU

The EU is a very significant funding source for health researchers and Ireland has a well-functioning support system to facilitate both input to policy-level discussions on its funding programmes and the submission of competitive proposals. National targets are set for the expected rate of success of submitted proposals and for the consequent draw-down of funds. Enterprise Ireland (EI) monitors and reports on the achievements of Irish researchers so that they, and their institutions, may augment their expertise and aim to increase their competitiveness. For the outgoing Framework 7 (FP7) period (2007 – 2013), over 8,000 Ireland-based applicants were involved in proposals with a success rate of almost 22% and some €572 million achieved. This was a significant improvement on performance in the preceding FP6. Of the total FP7 success, 1.65% of the funds available for health were attracted to Ireland. Awards for researcher mobility (Marie Curie) also contributed significantly to Ireland’s total while schemes such as ERC Fellowships and a range of others also contributed lesser amounts.

The overwhelming majority of funds (62%) were attracted to higher education with 26% to the private sector, including a number of Life Sciences companies. Among the public sector bodies that collectively attracted 4% of funds, both SFI and HRB were recipients, e.g. through Marie Curie CO-FUND. The (then) Irish Research Council for Science, Engineering and Technology and Irish Research Council for the Humanities and Social Sciences (now merged as the Irish Research Council, IRC) were also recipients.

Across all funding streams, Ireland achieved 1.45% of the available funding, against a target of 1.08% and gives cause for optimism in achieving its impressive target of €1.25 Billion during the seven years of Horizon 2020 that has commenced in 2014. Enterprise Ireland continues to provide incentives for applicants to EU programmes.

2.3.4 Irish Research Council (IRC)

The IRC was launched formally in March 2012 as a sub-board of the HEA. Its mission is to enable and sustain a vibrant and creative research community in Ireland. The Council enables the Irish research community to contribute to the body of global knowledge across a range of disciplines, recognising the importance of research and scholarship for all aspects of social, cultural and economic development. It aims to show how creativity, excellence and curiosity can go hand in hand for Ireland’s benefit by funding the best and the brightest researchers in Ireland. Membership of the IRC reflects the diversity of the research community in Ireland.

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*Fifth Interim Report of Irish Involvement in the Seventh European Union Framework Programme for Research and Technological Development (FP7). September 2013 Enterprise Ireland.*
The IRC has an advisory role to the HEA and a policy advisory role for the Department of Education and Skills and Department of Jobs, Enterprise and Innovation with regard to postgraduate research and the research system in general. An international outlook is also a key attribute of the IRCs work, in particular encouraging collaboration within the EU and interacting with a range of organisations that promote and fund research.

The IRC is in a distinct niche – providing seed-corn funding for the Irish research system in all disciplines. Most funding is for early stage research staff, i.e. in their 1st or 2nd post-doctoral position. The applicant success rate is some 15%. The IRC also supports structured PhDs for some 1,200 students across Ireland.

2.3.5 Charities

The MRCG has 4 goals for achieving its mission of creating a dynamic medical research environment in Ireland. These are:

- Increase the funding for medical research in Ireland
- Remove the barriers to medical research in Ireland
- Increase the profile of medical research in Ireland
- Provide the services and supports members require.

The MRCG is not itself a funder of research – that is the role of its member organisations (Annex D). In 2006, the (then) Department of Health and Children awarded MRCG €1m in the HRB allocation for the co-funding of research between the charities and the HRB. The amount awarded annually is now some €900k.

This innovative scheme allows members of the MRCG to support research of particular interest to patients where the charities in question might otherwise not be in a position to finance the full cost of that research. While no differentiation is made between charities or disease areas, the scheme has been particularly beneficial for rare diseases where research being undertaken internationally may be limited.

The MRCG partnership with the HRB has also helped to build capacity in Irish research charities, ensuring that they can operate to the highest standards and with regard to all elements of their research processes. The scheme is also important to encourage less experienced researchers to gain appropriate experience in a structured, supported scheme. The scheme operates as follows:

- Once funding procedures and a timeline for the scheme have been agreed by MRCG and HRB, MRCG member charities solicit applications from researchers. An individual charity selects its own closing date for its research call, ensuring that this will leave sufficient time for the submitted applications to be peer reviewed and progress as necessary through robust, transparent internal processes. For peer review, international reviewers are used to ensure best practice and independence. The charity subsequently uses its internal processes (clinical / scientific research committees) to ensure that applications are within the scope of the charity’s research strategy. Charities must only submit applications which they can afford to co-fund.

- The MRCG and HRB jointly appoint a panel of experts to review applications, operating in a similar way to HRB’s usual funding panel processes. The number of projects funded in any round of the scheme is determined by the funding available and the funding required for the submitted projects. All projects recommended for funding by the joint
panel, must be approved by the Board of the HRB. For any successful application, the relevant co-funding charity enters into a contract with the research organisation and funding is issued to the charity annually by HRB.

To date, six calls for funding have been approved and 89 projects for which funding might otherwise might not have been available, have been supported through this scheme.

2.3.5(a) A MRCG member with a larger research budget: Irish Cancer Society

In general, the Irish medical research charities are small – as is not unexpected with a small population base – with limited sums to invest in research. However the Irish Cancer Society is a relative exception. The funds available over its 50 years of existence have enabled a deliberate strategy to invest in research across the full spectrum from laboratory-based discovery research to its clinical application. Ongoing initiatives include scholarships, fellowships, projects and programmes. Now, since 2013, the Irish Cancer Society has embarked on a major initiative – Collaborative Cancer Research Centres, commencing with breast cancer.

These are virtual centres, bringing together the skills and expertise of the top cancer researchers in Ireland who are already working in the country’s leading academic institutions and hospitals. Participating in the centres are clinical researchers who work directly with patients, laboratory-based researchers, and population researchers who analyse data for cancer trends, patterns etc. The collaborations enable the combining of expert knowledge and information and are countrywide. Further centres will emerge based upon this model. The charity is also keen to play a role in developing an improved career structure for clinician scientists so that clinicians may gain research expertise through PhD training and apply their expertise in parallel with their clinical responsibilities.

The Irish Co-operative Clinical Research Group (iCoRG) was set up in 1996 with the aim of creating more research opportunities for patients through a formal structure. This would make Ireland more attractive as a location for international cancer research groups and the pharmaceutical industry. iCoRG is a not-for-profit registered charity funded by the Irish Cancer Society and HRB and is active in hospitals throughout Ireland. The iCoRG mission is to enable Irish patients to gain early access to new cancer treatments.

Since its incorporation iCoRG has opened 290 research protocols allowing access to potentially beneficial new treatments for more than 10,300 patients with cancer. The participation in iCoRG of researchers and oncologists based in Northern Ireland (NI) enabled the development of their expertise and, through co-funding by the NI Health Department and Cancer Research UK, the foundation of the NI Cancer Trials Centre and Network that, today, enable the participation in clinical trials of one in every seven patients who are diagnosed with cancer in NI.

iCoRG has also developed strong links with many leading international cancer research groups and those in industry developing promising new cancer treatments. As a result of these positive relationships Irish patients are now being offered cutting edge research options that previously would only have been available in the United States or Europe. iCoRG currently has studies open in a broad spectrum of cancers in addition to translational studies. An important part of the work of iCoRG is to facilitate the training of staff who are involved in research at its various sites. The staff include research nurses, data managers, investigators, research registrars, radiation therapists and research pharmacists.

2.3.5(b) A MRCG member with a smaller research budget: Fighting Blindness

This patient-led charity has existed for some 30 years. Its research strategy includes both fundamental and translational research and focuses on projects that have achieved world-leading discoveries about the genes that contribute to
blindness. This involves supporting genetic research that can lead to possible therapeutic interventions. A primary mechanism of its research support is to provide seed-corn funding for projects, including pilots, that wouldn't be fundable by others. Most projects then receive more significant funding from elsewhere and build up capability. Importantly, effort is made to fund all of the project costs, e.g. small items of equipment, to increase the likelihood of successful completion.

The profile of funded research is gradually moving more towards the clinic, e.g. genetic profiling of patients who may then be future clinical trial participants. However, the charity’s willingness to support this clinical research is not matched by the necessary action by the HSE.

The charity aims to ensure that patients are well educated about the benefits of research. Engagement among patients and researchers is generated through outreach and a range of communications. Fighting Blindness regards this type of partnership as important and growing.

2.3.5(c) Other MRCG member: National Children's Research Centre (NCRC)

The NCRC was founded in 1965 as the first dedicated research centre on the site of an Irish hospital (Our Lady’s Children’s Hospital, Crumlin). The Centre underwent major renovation and organizational changes in 2009 and now offers a state of the art facility for biomedical research and an additional Paediatric Clinical Research Unit. The goal of the NCRC is to facilitate research into the diagnosis, treatment and prevention of childhood diseases through the award of research grants funded by the Children’s Medical Research Foundation (CMRF). The NCRC also supports research into paediatric diseases at a number of other locations in Ireland and its grant award schemes are open to scientists and clinicians with relevant interests.

Through its funding schemes and infrastructural supports, NCRC is building a sustainable, national paediatric research community of scientists, clinicians, nurses, and allied health professionals. Part of its strategy is also to provide infrastructural supports for the development of paediatric research. Two related structures are used: The first is the development of its Paediatric Clinical Research Unit which provides statistical and data management support in addition to access to a clinical project manager, clinical research assistant and research nurse. The second is the programme to develop the careers of early stage paediatric researchers and to support clinical Principal Investigators through an MD/Clinical MD/ Clinical PhD/MSc.

2.4 Irish Platform for Patients’ Organisations, Science and Industry (IPPOSI)

IPPOSI is a patient-led partnership which facilitates stakeholder interaction on the development of policy, legislation and regulation on emerging medicines, products, devices and diagnostics, particularly in areas of unmet medical needs in Ireland. Its key stakeholders are patients’ organisations, science, industry and, where possible, state agencies. IPPOSI is not a lobbying organisation but it works to ensure that innovations in healthcare are available at the earliest stages to patients in Ireland. This represents a unique partnership on the island of Ireland.

The work of IPPOSI is undertaken through:
• Expertise
• Dialogue
• Consensus building
• Networking
The work of IPPOSI also has a significant international dimension, for example with the European Patients’ Academy on Therapeutic Innovation (EUPATI), where IPPOSI is seen as a lead organisation. IPPOSI is part-funded by the HRB.

2.5 Private sector

The Irish Pharmaceutical Healthcare Association (IPHA) represents the international research-based pharmaceutical industry in Ireland. Its members include both manufacturers of prescription medicines and non-prescription or consumer health care medicines. The mission of IPHA is to create a favourable economic, regulatory and political environment that can enable the research-based pharmaceutical industry in Ireland to meet the growing healthcare needs and expectations of patients.

Among the benefits provided by the IPHA is a Clinical Research Advisory Forum that enables sharing of views and information on clinical trials and the development of strategies to remove impediments.

Generally, IPHA member companies conduct Phase III and IV clinical trials in Ireland. As part of the initiative for greater transparency and better access to clinical trial information, companies register ongoing clinical trials and results of completed clinical trials on the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) clinical trial portal. The data from these clinical trials are then reviewed by the Irish Medicines Board (IMB) or other regulatory agency to determine whether the benefits of the medicine outweigh the risks.

Before authorisation to conduct a clinical trial is granted in Ireland an application with supporting medical and scientific data must be submitted to the IMB for medical and pharmaceutical review. The supporting data consist of laboratory and animal testing and tests for toxicity. This data are reviewed by the IMB to determine whether the drug is scientifically valid and properly researched at the pre-clinical trial stage. A positive opinion must also be obtained from a Research Ethics Committee (REC) which is independent of the pharmaceutical industry. Once authorisation has been received from the IMB and the REC, a clinical trial can be carried out by the pharmaceutical company or commissioned to medical / academic institutions, as well as specialist clinical research companies. The clinical trial must be conducted in accordance with Good Clinical Practice (GCP) and trials are audited by the IMB to ensure compliance.

To facilitate the effective initiation of trials and the removal of administrative barriers, a single HSE Clinical Trial Indemnity Form (HSE CTIF) has been agreed between the State Claims Agency and the IPHA for the conduct of industry-led trials in Ireland. This form is applicable to the conduct of any industry sponsored clinical trial in any HSE hospital.

2.6 Legislation

A draft Health Information Bill has been in preparation for some time by the DoH, informed by a public consultation9. The main objective of the Bill will be to strengthen the existing legislative base for the more effective use of personal health information throughout the health system. To that end it will:

• Provide an enabling legal framework for certain initiatives (such as data matching programmes and health information resources, a streamlined multi-site REC Structure, standards to promote better Inter-Operability of ICT systems)

9Discussion paper on Proposed Health Information Bill June 2008.
• Strengthen patient rights in relation to their personal health data
• Support patient safety by promoting adverse event reporting, open disclosure and quality improvement processes
• To help kick-start a change in culture in how personal information is used in the health system.

The aim of DoH is to publish the Bill by end 2014. As per above, the Bill is expected to include the potential for approved RECs to grant multi-site or national approval for health research studies (not otherwise governed by EU law which, for example, already regulates clinical trials). The Health Information and Quality Authority (HIQA) will have supervisory oversight of the approved RECs. Local RECs will not be affected by the new system but HIQA will have a role in promoting better overall quality of all RECs.

One major element intended for inclusion in the Health Information Bill was deemed to be more urgent (in the context of initiatives like Money follows the Patient) and was brought forward in December 2013 as the Health Identifiers Bill. The purpose of that Bill is to provide for the assignment of health service identifiers for use in the public and private health service and for the related governance framework. The Bill provides for the assignment of unique health identifiers to individuals to whom a health service is being, has been or may be provided and for the assignment of unique identifiers to health services providers. A national register of individual health identifiers and a national register of health services providers are to be established containing the identifiers and other relevant information. Implementation of a unique identifier system is recognised as being an essential infrastructural initiative which will facilitate many significant improvements to the health system in areas such as patient safety and improved data access and quality leading to improved overall systems efficiency. It is also a fundamental requirement for deploying eHealth solutions and the Department released its eHealth Strategy on the same day as the Bill was published.

The Health Identifiers Bill does not change the current data protection law on the collecting, use and disclosure of personal data, including personal health data. Health identifiers can be used in health research projects where the research and the person carrying it out are compatible with the provisions of the Bill especially as regards the permitted relevant purposes set out in the Bill.
Study Methodology
3.0 Study Methodology

The principal objective of the study fieldwork was to gain understanding of the views of researchers and stakeholder organisations on the current health research funding environment in Ireland. Throughout the study and in this report, no comments received are attributable to any individual or any organisation save where explicit permission to do so was received from that person or organisation.

3.1 The views of Researchers

An initial letter of invitation to participate in the study was sent to each university by email addressed to senior academic staff (Vice President / Dean) with responsibility for research. Those who indicated their willingness to participate then received a briefing email (Annex A). Arrangements were made both for further discussions with the senior individual and focus group meetings with other researchers invited by the senior individual, at whatever career stage from research student to professor / principal investigator (PI). Attendees included both university-based researchers, others with clinical responsibilities and research or innovation support staff. All discussions were semi-structured in that a series of potential questions was shared in the advance briefing. Interviews / focus groups proceeded generally in line with those questions. In a number of cases, additional one-to-one meetings or phone calls were arranged with researchers.

In parallel with the discussions and focus groups, an online survey was developed by MRCG to enable (anonymised) responses to a series of questions. The web link to the survey (on Survey Monkey) was distributed to universities via Research Offices. The survey enabled responses to direct questions in addition to free-form text comments. All survey questions, quantitative information on the direct responses and summaries of the textual contributions are included at Annex B. There were a total of 190 responses. The nature of qualifications, employment and research undertaken by respondents shows that, as with the focus groups / interviews, views were elicited from a broad sample of researchers (Table 3).
Table 3: The profile of online survey respondents.

<table>
<thead>
<tr>
<th>Place of Work</th>
<th>University</th>
<th>Other 3rd level</th>
<th>Hospital or other Health Service</th>
<th>Industry</th>
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<table>
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<th>Contract</th>
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<td>63.2</td>
<td>31.1</td>
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<th>Masters</th>
<th>PhD</th>
<th>MD</th>
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<td>6.8</td>
<td>21.6</td>
<td>61.6</td>
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<table>
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<th>Years since highest qualification</th>
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<th>6-10</th>
<th>11-15</th>
<th>16-20</th>
<th>&gt;20</th>
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<td>24.2</td>
<td>20</td>
<td>10</td>
<td>15.3</td>
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</table>

<table>
<thead>
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<th>Nature of Research</th>
<th>Lab Early phase Biomed</th>
<th>Lab Late phase Biomed</th>
<th>Clinical</th>
<th>Health Services</th>
<th>Population Health</th>
<th>Policy</th>
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<td>25.8</td>
<td>47.4</td>
<td>27.9</td>
<td>18.9</td>
<td>10</td>
</tr>
</tbody>
</table>

* Rows can total more than 100%, e.g. researchers may work in a university and a hospital / health service setting.

Key: The highest prevalence; The second highest prevalence

### 3.2 Stakeholders

Face-to-face or telephone interviews were carried out with a wide range of representatives of stakeholder organisations including MRCG member charities, health research funders, Government officials and others, i.e. broadly representative of the organisations that are detailed in Section 2. These interviews were less structured than the discussions with researchers as the topics covered varied according to the remit of the particular organisation.

### 3.3 Steering Group

As the study progressed and findings emerged, they were presented at meetings of a Steering Group convened by MRCG. Chaired by the MRCG Chairman, other Steering Group members included representatives of: MRCG member charities, HRB, IRC and the Irish Universities Association (IUA). Three meetings took place and provided a forum for challenge to, and robust discussion of, the study report to ensure its accuracy, clarity and robustness.
3.4 MRCG Conference

A conference was organised by MRCG (November 12th 2013) with a range of speakers, including the Minister for Research and Innovation, to raise awareness of the study and enable presentation and discussion of initial findings. An excellent attendance represented the breadth of health research and provided valuable insights that have been incorporated into this report. A conference outcomes report is available on the MRCG website www.mrcg.ie.
THE HEALTH RESEARCH LANDSCAPE IN IRELAND:
WHAT RESEARCHERS SAY

Study Findings
4.0 Study Findings

This section is structured around five themes based upon the predominant comments from researchers, stakeholders and survey respondents. While the themes were selected by the study author, the views expressed are solely those contributed by study participants through a combination of the various methods outlined in Section 2. The five themes are:

- Enabling Infrastructure
- Doing Research
- Research Careers
- Using Research
- Patient Advocacy

4.1 Enabling Infrastructure

This term is used extensively to refer to human, physical and data resources that support research. Such infrastructure transcends individual projects or programmes of research, is available for use by multiple researchers / multiple projects and should be sustainable. Ideally, such infrastructure should be supported by a financial model that enables re-investment in an expanded infrastructure. Typical elements of an enabling infrastructure are: biobanks, databases, research nurses, other health professionals dedicated to research, data managers, health economists, administrative staff and appropriately-appointed and equipped CRFs. Enabling legislation may also be considered as infrastructure, e.g. that concerning access to health-related data. Infrastructure should also enable and support collaboration among different research groups, located at different sites but all sharing the infrastructure.

The views expressed in relation to infrastructure were:

- A lot of previous research funding went for buildings and equipment. These are vital for high quality research but it takes time to deliver robust research findings that can be communicated to demonstrate a return on this investment
- CRFs are very helpful, but there is little clarity about how these will be sustained beyond current funding. There was also a suggestion that CRFs tend to isolate research into particular parts of a hospital instead of being embedded in all areas
- Research nurses are essential but outside of CRFs there is no job security as they are employed on a project-by-project basis
- The lack of a proper, connected electronic healthcare record system where every person in Ireland has a unique number is an impediment
- Data protection needs to be addressed
- There is a lack of knowledge and awareness of legislation and ethics among some researchers
- There is inconsistency in the work of RECs and what they consider to be their remit. Multi-centre studies pose particular problems. One study that involved less than 1,000 participants required approval from 138 separate RECs
• The national indemnity cover arrangement for clinical research is most helpful
• Support for areas such as paediatrics or rare diseases is often overlooked as is support for research in primary care
• Where HSE provides support for clinical research, it is very welcome. This includes permission to use clinical space without special payment. However, for some hospital space, research centres do have to pay rent. Overall, this support is *ad hoc*, not formalized
• Collaboration among academic researchers and clinicians is restricted because the HSE does not employ researchers, even if they have external funding
• Project funding does not normally contribute funding to running or maintaining research infrastructure. This is compounded by the lack of overhead allowance in awards from charities
• The new hospital group arrangements stemming from implementation of the Higgins Report are expected to be helpful. They will provide a focus for direct university – HSE engagement
• Where there are patient databases, e.g. the National Intellectual Disability Database held by HRB, the impact on research is transformative (See Case Study at the end of Section 4).

Survey respondents (Question 10, Annex B) indicated that the primary infrastructure elements that impact negatively on their research are (in order of % of respondents who agreed or strongly agreed): Lack of a relevant patient registry (57%); Challenges relating to ethics committees (45%); Challenges relating to clinical trial infrastructure (38%); Lack of a relevant biobank (37%); Lack of legislation to govern the use of patient data (19%); Lack of legislation to govern the use of human tissue (14%).

4.2 Doing Research

This category of responses considers primarily the attraction of funding for research projects or programmes and the ability to develop research teams with the appropriate range of scientific, clinical or other expertise.

From the survey, of those respondents who had sought research funding in the past 3 years, 59% indicated that the current economic climate had had a ‘slightly negative’ or ‘very negative’ impact on their ability to attract Irish research funding. (Question 6, Annex B). Of those who had experienced difficulty, the predominant reason given (41% of respondents) was that their research would not lead to economic benefit in the short term (Question 7, Annex B).

Through the survey questions that enabled free-form text responses (Questions 13, 14 Annex B), and the focus groups / interviews, the single most frequent comment was the need for a better balance in funding opportunities between more applied clinical research and fundamental, discovery research, including research at the earliest translational stages.

In Survey Question 7, 25.7% of respondents indicated that the fact their research did not align with one of the NRPE priorities was a reason why they had experienced difficulties in attracting funds. Question 8 probed further, listing eight of the 14 priorities, and 45.4% of respondents indicated that their research did not fit with any of the 8 areas. However a number of respondents also highlighted the relevance of their work to ‘Diagnostics’ – one of the NRPE priorities that was omitted from the survey list in error. Thus it is safe to say that the work of over half of all health researchers who completed the survey aligns with the NRPE priorities.
Other comments:

- Projects at intermediate stages between discovery and being ready for application to clinical contexts are affected significantly.
- HRB awards focus on clinical trials, with some pilot / feasibility work. But what about earlier stages e.g. observational work to shape the study design?
- Clinical researchers support the objectives of particular charities, and charities are pleased to support research groups, even for the longer term. In general, there is a feeling that charities enable flexibility with funding so that successful completion is more likely.
- For institutions, there are no overhead funds from charities (no standard process to calculate full costs) and no government funds to overcome the shortfall.
- The lack of overhead from charities applies also to awards from Wellcome Trust – both their own portion and to the portion from HRB or SFI.
- Many charities have small budgets for research. But some add significant value by providing seed-corn funding. It was suggested that others might do the same, targeting the preparation of proposals for subsequent major funding. A positive example of where this has worked is with EI funds that facilitate project development, preliminary data collection etc - these awards have increased the ability to attract EU R&D Funds.
- There is a perception that a number of established researchers continue to monopolise charity funding even though they are well-placed to submit proposals to larger, government funders. Thus less well established researchers are crowded out.
- Researchers value the MRCG-HRB scheme, though some expressed concern that the 2-stage review process represented a 'double jeopardy.' (The scheme is detailed in Section 2.3.5)
- The tendency for funders to invite applications only for very specific areas of research is seen as a disadvantage to many whose work is not in those particular areas or is more broadly relevant.

A number of survey respondents and others indicated an opportunity for a greater extent of collaboration, primarily among clinicians and research scientists (Question 13, Annex B).

### 4.3 Researcher Careers

The challenge for early stage, post-doctoral researchers (post-docs) to gain permanent posts is global. The ‘traditional’ model is for each person to progress through several periods of contracted research, all the while accumulating experience and increasing their number of research outputs. In Ireland in recent years this challenge has been compounded by a number of supply and demand factors, most notably a moratorium on permanent public sector appointments – including in higher education - and an increase in the number of PhD students. While PhD training is highly beneficial for entry to a range of Life Sciences industry posts, those who opt to stay within academia currently face considerable challenges. Thus, in answer to survey question 13, seeking suggestions of what might be changed in the Irish health research environment, it is unsurprising that issues around careers and opportunities for post-docs predominated.
During focus group meetings, while non-permanent staff could see the appeal of having permanent research posts, others were more concerned with the need to be able to apply for external funding in order to continue to pursue their research areas and build the kind of profile that would more likely lead to future permanency (an academic post).

It is not unusual for external project funding to be available only to holders of permanent posts; however the continuation of that approach during a time of moratorium on permanent posts has created a particular difficulty. This affects staff appointed to fixed-term academic posts as well as post-docs; however universities tend to be more likely to facilitate external applications from academics.

The lack of a defined career pathway for researchers creates many uncertainties, compounded by the criteria for a number of fellowship opportunities that specify the duration of post-doctoral time that applicants are expected to have. There has not been a trend in Ireland to build large career blocks through externally funded personal fellowships even though such awards are provided by the Wellcome Trust. With the current focus on pursuing Wellcome Trust awards, to be successful in competition with those from UK institutions who have more experience of this type of career-building, applicants from Ireland see the need to plan their careers more pro-actively and obtain support to do so.

The stumbling-blocks encountered by researchers, whether in post-doc or academic posts, are most acute at intermediate career stages, i.e. when individuals would usually seek to consolidate their research groups/careers. Barriers include:

- The need to have been a PI on a previous study is now a requirement for HRB funding. How do early stage researchers secure their first award? (A welcome note: HRB has indicated that this criterion will not continue)
- The paucity of Fellowships to apply for once a person has completed 6-7 years post-doctoral work and wishes to remain in a research post.

The difficulty in gaining personal recognition for work done was highlighted and is captured in the following:

‘While I am allowed to compile grants applications, ultimately they will be submitted under the head of the research group, which in turn impacts on my career.’

The interpretation in Ireland of the EU Fixed Term Working Directive has led to deterioration in job security for research staff. Employing institutions work to ensure that no research staff can achieve the qualifying criteria for permanency, e.g. a contract of longer than 4 years or progression from one fixed-term contract to another.

‘We often have to let very good staff go due to fears and concerns and rules and regulations of a system that seems to be characterised by an increasing paranoia around the legalities of research staff contracts.’

Taken together, the pressures on research staff have led to a perception that remaining in Ireland is detrimental to career prospects, e.g. the following response to survey question 14:

‘The mood (among researchers) is so low that most actively discourage students from embarking on a career path that results in nothing but job instability, forced emigration, lack of recognition for the role played and a feeling that you are seen as a disposable liability that can be used for 3-4 years but gotten rid of before you can have any hope of establishing a career in research.’
For health services research, those in primary care, including General Practitioners, face particular challenges, e.g. due to their career training and dispersed working places. This was recognised previously however previous report recommendations have not been implemented (Mant report).  

Finally, gender-related patterns of researcher careers in Ireland are similar to those elsewhere: a gradual attrition of females during progress towards senior levels. It is important that research funders work to minimize this and SFI’s scheme for women returning to science is a good example.

4.4 Using Research

Health research funds are provided for work that aims to address a particular outcome or impact. The range of potential impacts is diverse but includes: improved patient outcomes, better services, better population health, better policy-making, economic development etc. But researchers alone, even if working within strong, multi-disciplinary teams, cannot have the responsibility alone of achieving any of these outcomes. The users of the research findings must also be involved.

The diverse outcomes relate also to a diversity of research users, whether in government or business, health service providers or health service users, members of the public or health professionals. Productive engagement among researchers and research users is a challenge that is being faced in many countries and is a current pre-occupation of EU Commission research leaders.

A great many different strategies are employed in endeavouring to gain the necessary engagement and, because it requires the time and resources of researchers and other staff, also requires investment beyond the initial research funding.

If potential research users cannot realise the benefit of this engagement, it is unlikely that they will be supportive of continued funding of health research.

With regard specifically to the achievement of health benefits – whether for service provider organisations, patients or the population – the ability to undertake research in clinical environments (clinical trials and other studies) is vital, followed by the implementation of any advances and their embedding in practice. Funders such as the HRB and some charities are now focusing on supporting clinical research within health services, and EU Horizon 2020 is expected also to support this work - however there is no real engagement with the HSE so that findings can be implemented.

Survey question 14 asked for any additional suggestions and a number centred on ways in which research users might be engaged. However most of these depend upon the creation within health service organisations of a culture that values research as an asset that can help to improve its clinical and cost efficiency as well as clinical efficacy.

Users of research also include Life Sciences businesses. Through a range of initiatives and mechanisms this is enabled particularly by SFI and EI. However if a country is to benefit from its research-derived intellectual property, those businesses need to be facilitated to invest. Most of the companies with a base in Ireland do not undertake R&D within

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12 Science Foundation Ireland Advance Fellowship Programme, February 2014 www.sfi.ie/assets/media/files/downloads/Funding/Funding%20Calls/Advanced%20Fellowship/2014%20Advance%20Fellowship%20Call%20Doc.pdf
this country, and do not create large numbers of jobs for researchers. However their investment in research enables the (continued) employment of highly educated, trained and experienced researchers in academia. This is becoming a stronger element in Ireland’s suite of attractions for global industry investment however its growth will be restricted if the current clinical research infrastructure does not improve at least at the same rate as in other countries, e.g. access to biobanks and databases, an efficient national REC system etc.

4.5 Advocacy

Patients (service users) are highly supportive of health research, citing the possibility of benefits for themselves, their families or others. To really understand research and therefore articulate to politicians and other decision-makers what is needed to enable such research, it is critical to involve patients and other lay people in all stages of research. Their involvement only as study participants is insufficient.

Charities provide excellent means of engaging patients and researchers and this is a strong focus of the work of a number of MRCG member charities. Patients or other lay people need to be trained to engage effectively and to inform the details of various stages in research projects. But where this has been done, researchers benefit considerably.

An additional step is to find ways through which research-engaged patients can engage effectively with government and public sector bodies such as the HSE to increase their support for research. Again, patients and their advocacy groups need to be provided with detailed information on the return on investment in health research being achieved in Ireland. The networking of researchers with each other and with patient groups could be advanced significantly through social media.

For a range of EU Horizon 2020 funding programmes, consortia will require the involvement of patients. While IPPOSI is well placed to support this, the buy-in of researchers requires development.

An exemplar research project that engaged patients and their carers very effectively for better research and better dissemination of findings is the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). The following vignette demonstrates how that project dealt with some of the current barriers to health research while showing how best practice in user involvement could be achieved. Fuller details are at www.idstilda.tcd.ie

**Exemplar Study:**

Excellent participant and carer involvement;

Using well-maintained national infrastructure (database);

Dealing with overlapping research governance.

**Intellectual Disability Supplement – The Irish Longitudinal Study on Ageing (IDS-TILDA)**

This study aimed to compare the experience of ageing for people with an intellectual disability (ID) relative to people in the general population. It was the first of its kind in Europe. For people with an ID, the study also explored health, health service needs, psychological health, social networking, living situations and community participation. It was funded by HRB and the
(then) DoHC. Consent to participate was obtained from 753 people whose personal identification numbers (PINs) were selected randomly from over 26,000 in the National Intellectual Disability Database (HRB, 2011). Confidentiality was maintained by Regional Database Coordinators who passed survey materials to the participants on behalf of the researchers.

The study report (Growing Older with an Intellectual Disability in Ireland in 2011: First Results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing) details the ID population in Ireland during a time of transition from institutional congregated living to community living. It is a very significant asset through which to monitor the impact over time of this policy.

Ethics approval was received from the TCD Faculty of Health Sciences REC. Study participants were linked to 138 service provider organisations so, over an 18 month period, separate ethics approval had to be sought from that number of regional and local RECs. This was despite some overlap in membership between the different RECs. Some RECs asked the study team to prepare hardcopy papers for REC members and some required the PI to attend its meeting. This was an extraordinarily resource-intensive process.

The study is a great example of what can be achieved when:

• In all stages of this study, including dissemination of findings, people with intellectual disability are included as part of the study team

• There is well-maintained national database with regional staff to support researchers and ensure confidentiality for people who are included

• Researchers focus on delivering an asset base of knowledge about a representative population on whom future studies can be based

• The study team voluntarily commits significant personal time to repetitive ethics approval processes.

The true impact of the work will be achieved if, and when, the providers of services, including health services, for people with ID, make use of the comprehensive data compiled through IDS-TILDA. Some of this is already happening.
Discussion
5.0 Discussion

Health research in Ireland has a number of highly positive features and advantages that enable the performance of high quality research with the potential to yield clinical, academic and economic benefits. Chief among these is the sustained availability of national funding despite more than five years of severe public sector financial constraint. This advantage is clearly evident to the researchers and other stakeholders who commended this reality when providing input to this study. However changes in the pattern of research that is funded, while appropriate for enabling a greater return on investment in the relatively short term, risk undermining essential areas of work that are both excellent and highly productive.

The major strategic approach to achieving beneficial returns on investment has been the NRPE. However the outcomes underpinning that initiative relate predominantly to the economic sector. It is not surprising, therefore, that implementation of the NRPE has not been beneficial for all aspects of health research. This unintended consequence is exacerbated by a range of concurrent systemic challenges, e.g. controls on exchequer-funded public sector recruitment, implementation of EU employment directives in way that is not favourable to researcher careers; organisational and cultural changes in the provision of health services and extensive change in national and global higher education structures.

Many other countries have implemented a range of measures to assure themselves that research funds are allocated to support excellence; that areas identified as excellent are strengthened and that the hosting of research does not impose a financial burden on academic or clinical institutions. Ireland has not yet progressed to a full national research assessment process, and of course that is not essential for achieving excellence. However that absence leaves some uncertainty over the adequacy of research funding or other support for areas of research that genuinely are strong and capable of making a major impact. Additionally, the lack of funding to support institutional costs of research (aka overheads) poses a real risk to the ability to maintain the research infrastructure that is now being put in place through a range of initiatives.

Charities do not provide overheads, regardless of the extent of their resources. The UK provides dedicated funding to institutions in proportion to their research income from charities. For Irish researchers and research institutions that could be a positive incentive for targeting significant charity funding, e.g. Wellcome Trust. That 'top-up' could be carved out of existing funders' budgets, its scale would not be detrimental to any area but would benefit many.

However important the research funding may be, it is just one element in a series of enablers that are necessary to achieve a return on investment in research. The returns on such investment in health research should be evident within health services, the health and wellbeing of the population and within the economy, in addition to high quality academic contributions to the global body of knowledge and progress in academic careers. While the HSE senior management are very positive about the benefits of research, the preferred routes for engaging with and enabling research in sustainable and transparent ways need to be restated by the leadership of revised health service structures.

While Ireland's current set of health research enablers and barriers is relatively unique, it is not the only country coping with challenges. Thus by clearly understanding its research enablers and barriers, and implementing solutions that have proven beneficial elsewhere, it should be possible to achieve many desirable outcomes.
The Health Research Landscape in Ireland: What Researchers Say

Recommendations
Recommendations

6.1 To effect beneficial change, five strategic actions are recommended, together with a mechanism to maintain engagement of the principal players.

1. Develop and publish a vision for Irish health research

This might be a succinct statement setting out the state of the landscape in the next year, 5 years, 10 years and beyond and the benefits that can be delivered through health research. This would provide clarity to researchers and their organisations on the types of desirable impacts of their research and might include statements such as:

- Ireland has a strong commitment to partnership working among public, charitable and commercial health research funders focusing on delivering benefits for people’s health and for the economy.

- In 1 year Ireland will have a seamless funding landscape that enables fundamental research discoveries and their translation to patient benefit, with opportunities for a high proportion of patients to participate in clinical trials. Support for excellent skills among health researchers based in academia and health service organisations will be a high priority.

- In 5 years Ireland will have a comprehensive, effective, efficient health research infrastructure to combine state-of-the-art fundamental and clinical research facilities, clinical study networks, bio-repositories, patient cohorts and databases to enable the conduct, translation and implementation of world-class research. The impact of research on people’s health and health services will be demonstrable.

Two relevant examples from the UK have been highly influential. The first, from the Academy of Medical Sciences, revises the rewards: a vision for UK medical science. Academy of Medical Sciences, UK 2010. The recent publication from the Association of Medical Research Charities, Our Vision for Research in the NHS, Association of Medical Research Charities, May 2013.

2. Undertake an analysis of the pattern of health research funding availability

Individual research funders have profiled their pattern of allocations to projects and programmes thereby ensuring progress towards their objectives. However this does not highlight any gaps between different funders – a dominant theme among responses from researchers in this study. Such analysis could be undertaken with regard to the full spectrum of research from discovery through to implementation in practice, or with relevance to the burden of illness in Ireland. An example of such activity is the UK Health Research Classification System www.HHRCSonline.net

A review of funding requirements to maintain infrastructure would also be warranted.

3. Undertake an analysis of support for health research careers

A considerable emphasis has been maintained on developing initial research skills, especially through PhD studentships. While many PhD graduates will work in industry, academia and health services also need to retain
high quality researchers and, importantly, to enable them to undertake research in parallel with university teaching or clinical service responsibilities. Analysis of funding and career development opportunities can determine how systemic are the issues highlighted in this study. Consideration of evidence on all career stages, for both males and females, can reveal any ‘leakage’ points that may reduce Ireland’s ability to capitalise on its investment in early stage research skills. A focus on clinical research contexts can reveal the enablers that would ensure career-long research productivity.

4. Use a process to prioritise research questions for policy, practice and services

The potential users of research frequently engage with research findings only as and when they need them. In practice, it is not always possible to access findings from robust studies that provide exactly the required, context-specific evidence.

Prioritisation of research questions is an evolving practice but one that very significantly supports engagement among researchers and potential research users. This is an area in which charities can play a very significant role, using any of a range of mechanisms to collate the views of their supporters on the research questions they would wish to have answered within the remit of the particular charity. The questions can then be refined through further consultation within and outside of the charity sector.

Prioritised lists of questions can then be highlighted – on websites or other literature – and used by researchers when preparing funding proposals and / or by research funders to initiate new programmes and solicit proposals. The James Lind Alliance is one organisation that facilitates the prioritisation of ‘uncertainties’ – aspects of health care that lack robust evidence for policy or practice. www.lindalliance.org

5. Maintain an overview on the comprehensive involvement of health service users and other lay people as partners in funding allocations and in research projects

Engaging with service users, e.g. patients, clients, carers and other lay people, has been shown in studies undertaken in other countries to improve the relevance and quality of research and the likelihood of achieving beneficial outcomes. Participation in research prioritisation is one aspect however people can be involved as research partners throughout all stages of a project and add significant value. Many research funders will no longer allocate funding for projects without evidence of an intention to include robust engagement. It is essential that people are trained appropriately for these roles and that researchers are made aware of good practice that they might adopt. Several relevant strategies have been published, for example15,16.

As a robust mechanism to realise these developments an Irish Health Research Forum (IHRF) is recommended.

6.2 Practical Considerations

It is recognised, and detailed in this report, that several groups in Ireland have undertaken work and published findings that would align with the five strategic actions outlined above. However this has never been done with an overt focus on patients / the public and health services as the end-users of the research findings. Nor has it ever included the health research charities sector. While these two changes would represent a significant shift away from collaborative discussions led predominantly by Government Departments and their bodies, such approaches have delivered benefit elsewhere, e.g. the UK Clinical Research Collaboration www.ukcrc.org; Canada’s Strategy for Patient-Oriented Research (SPOR) www.cihr-irsc.gc.ca/e/41204.html

Members of the Forum could include:

• Government Departments
• public sector health research funders: HRB, SFI and IRC
• charities: MRCG
• the HSE: when operational, the Hospital Groups may provide this representation
• industry: representational (umbrella) bodies, not individual companies
• higher education: a representational body, e.g. IUA
• Patients / service users: a representational body, e.g. IPPOSI

Core principles for the Forum might include:

• All Forum members would have equal standing regardless of the size or nature of the member organisation
• The Chairperson would be independent of any member organisation but would command respect both among health researchers and wider society
• Forum meetings would not be frequent – perhaps x 3 annually – and attendees normally would be the most senior officer of the organisation
• The Forum would not be a funding body; its work would be funded by its own members and members, in full or in part, might agree, from time to time, jointly to create a funding initiative to address a specific deficit
• The Forum would decide whether to establish an executive to support its meetings and / or to deliver other outputs agreed by its members; or to adopt a partner-led approach in which members would agree to support a piece of work on behalf of all partners. This type of decision would influence greatly the amount of resource available to take forward the strategic actions agreed by the Forum
• The Forum would not develop strategies but its analytical and other work would be informed by existing strategies etc that have not (yet) been implemented in full
• A strength of the Forum would be its ability to create a single voice on behalf of the health research sector.
Conclusion
7.0 Conclusion

This report has set out the views of researchers and other stakeholders on the current health research landscape in Ireland, particularly with regard to funding. The MRCG is well-placed to lead the implementation of the strategic recommendations, securing the involvement of the other proposed members of the Irish Health Research Forum.
THE HEALTH RESEARCH LANDSCAPE IN IRELAND:
WHAT RESEARCHERS SAY
Annexes
Annex A: Project briefing and questions

The Health Research Environment in Ireland

Purpose of the project:
To obtain current and solid information on the health research environment in Ireland, in a changing landscape. The results will give MRCG an evidence base for their advocacy work, will help guide future strategy and will provide material for public affairs and communications functions.

Methodology:
- Review of policy documents + interviews with key policy-makers
- Review of research funding strategies + interviews with funding bodies
- Survey of health researchers
- Interview with senior academic – clinical research managers
- Focus groups with academic – clinical researchers at all stages of research career.

Focus Group Questions / points for consideration

About health research in general
What are your general perceptions of the environment in which you are working?
Do you see any barriers that are inhibiting:
  A. the discovery and development of new knowledge about how to prevent, diagnose or treat illnesses?
  B. the translation of knowledge from research into new products, practices or advice?
  C. the embedding of knowledge, products or practices into health services?
Is the drive for economic development via R&D a barrier or an asset?
What is working well to overcome the barriers or otherwise support the work mentioned in A, B, C?
In what way is the support from Ireland’s medical research charities helpful? With the same amount of money as currently, how might they be more effective?

About your own research
Have the recession and austerity impacted on your research programme?
Do you see any barriers or gaps in support – not just funding – that might inhibit the realisation of goals set out at the start of your programme of work?
In what way do you ensure that members of the public are involved in your health research – not just as study participants but as partners in the research endeavour?
Do you interact with any of the charities that provide funds for health research in Ireland?
About you

How do you view your future career prospects – especially a career that would continue to contribute to health research?

Have your employment conditions changed in the past 2 – 3 years / since you started this job?

Has this position enhanced your skills and abilities to contribute to health research that will yield benefits for patients? The population? Economic assets?

Would you recommend health research as a good career? Why?

Finally, do you think any of your responses would have been different a year ago, or two years ago?

Interview questions / points for consideration by senior university staff

Is the university’s strategy for health research being realised?

In what way would your success be beneficial for patients or the population in general?

Is the drive for economic resurgence based on R&D compatible with delivering benefits for disease prevention, diagnosis, treatment or care?

Is the health research environment becoming more supportive, or less? What are the current barriers? Are new barriers emerging? What is working well?

How positively or negatively do you view the current academic / clinical interface (organisational and / or individual staff)?

Are there any organisational-level formal communications structures with health service providers? How are you expecting that to change in coming years?

In what way is the support from Ireland’s medical research charities helpful? With the same amount of money as currently, how might they be more effective?

Does your university interact specifically with any of the charities that provide funds for health research? How is any partnership recognised by your institution?

Do you have a strategy for ensuring that members of the public are involved in your health research – not just as study participants but as partners in the research endeavour?

Finally, what would you point to as indicators that health research in your university is delivering benefits for patients, health services and / or the health of the population?
Annex B: Survey Findings

Question 1: As a health researcher, which of the options below best describes your place of work? (You may select more than one option.)

- University: 60.0%
- Other third level institution: 10.0%
- Hospital or other health service setting: 20.0%
- Industry setting: 0.0%

Question 2: Which option best describes your current status?

- Permanent employee: 60.0%
- Contract employee: 30.0%
- Student: 10.0%

Question 3: What is your highest qualification?

- PhD: 30.0%
- Masters: 50.0%
- Undergraduate Degree: 10.0%
- MD: 10.0%
Question 4: How many years is it since your highest qualification?

Question 5: How would you describe the nature of your health research? (You may tick more than one)

Question 6: What impact has the current economic environment had on your ability to attract Irish research funding for your work in the last 3 years?
Question 7: If you have experienced difficulties in obtaining Irish funding for your research in the last 3 years, please tick which of the reasons listed below apply (you can tick more than one).

- My research will not lead to patient benefit in the short term
- My research will not lead to economic benefit in the short term
- My research does not fit within one of the 14 State research priorities areas
- My research plans were well reviewed but not funded due to lack of budget
- My research plans were not well reviewed
- Other

Question 8: The Irish government has set out 14 priorities for research.

- Data Analytics, Management, Security and Privacy
- Innovation in Services and Business Processes
- Connected Health and Independent Living
- Food for Health
- Therapeutics - Synthesis, Formulation, Processing and Drug Delivery
- Medical Devices
- Processing Technologies and Novel Materials
- Digital Platforms, Content and Applications
- None of the above
Question 9: With regard to the Research Prioritisation exercise, could you suggest one or more additional health research priority areas that you would like to see included in future research prioritisation?

<table>
<thead>
<tr>
<th>Suggested Priority</th>
<th>No. of times</th>
</tr>
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<tbody>
<tr>
<td>Basic / biomedical research</td>
<td>15</td>
</tr>
<tr>
<td>Health Services</td>
<td>12</td>
</tr>
<tr>
<td>Translational medicine</td>
<td>9</td>
</tr>
<tr>
<td>Disease aetiology</td>
<td>8</td>
</tr>
<tr>
<td>Child / young people’s health and wellbeing</td>
<td>7</td>
</tr>
<tr>
<td>Rare Diseases</td>
<td>7</td>
</tr>
<tr>
<td>Diagnostics</td>
<td>6</td>
</tr>
<tr>
<td>Disease treatment / Therapeutics and vaccines</td>
<td>6</td>
</tr>
<tr>
<td>Patient focused / Patient outcome measurement</td>
<td>6</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>5</td>
</tr>
<tr>
<td>Data / Patient Databases</td>
<td>4</td>
</tr>
<tr>
<td>Cancer</td>
<td>3</td>
</tr>
<tr>
<td>Core clinical research infrastructure - IT, nurses, project management</td>
<td>3</td>
</tr>
<tr>
<td>Infectious Diseases</td>
<td>3</td>
</tr>
<tr>
<td>Mental Health</td>
<td>3</td>
</tr>
<tr>
<td>Psychosocial / socio-cultural aspects of health</td>
<td>3</td>
</tr>
<tr>
<td>Health workforce issues - absence, competence, multi-disciplinary teams</td>
<td>3</td>
</tr>
<tr>
<td>Chronic illness management</td>
<td>2</td>
</tr>
<tr>
<td>Disease prevention</td>
<td>2</td>
</tr>
</tbody>
</table>

Other priorities suggested at least once: Antimicrobial resistance, Best practice guidelines, Bionanotechnology, Dementia, Excellence, Genome research and related health impact, Global health, Horizon 2020 priorities, Implementation Science, Involving patients more in their healthcare, Measuring the effect of public policy on health, Quality of life, Respiratory disease, Regenerative medicine, Tissue engineering, Patient safety.
Question 10: Please indicate the degree to which you agree or disagree with the following statements. My research has been negatively impacted due to:

- Lack of legislation to govern the use of patient data
- Lack of legislation to govern the use of human tissue
- Lack of a relevant patient registry
- Lack of a relevant biobank
- Challenges relating to ethics committees
- Challenges relating to clinical trial infrastructure

Question 11: If you are NOT employed in a permanent position, please indicate the degree to which you agree or disagree with the following statements: My research has been negatively impacted due to:

- Lack of defined career structure for researchers
- Institutional policies seeking to limit the time spent in one institution
- Lack of employment opportunities in Ireland
- Lack of recognition for duties undertaken in addition to research e.g. undergraduate or postgraduate supervision, teaching, project management, administration
- Not being permitted to apply for funding in my own name, due to lack of permanency
<table>
<thead>
<tr>
<th>Suggestions</th>
<th>No. of Times</th>
</tr>
</thead>
<tbody>
<tr>
<td>A more appropriate balance of funding between basic and applied research</td>
<td>10</td>
</tr>
<tr>
<td>Greater discussion and collaboration among clinicians and (academic) scientists</td>
<td>9</td>
</tr>
<tr>
<td>Funding that early career researchers and [non-permanent] post-doc, research staff can apply for</td>
<td>8</td>
</tr>
<tr>
<td>Clearly set out, professional / career development [for post-docs]</td>
<td>7</td>
</tr>
<tr>
<td>Clinicians to have protected time for research</td>
<td>6</td>
</tr>
<tr>
<td>Clear, defined roles and positions for post-docs, incentives for them to remain in the country, either salary based or relating to job security, recognising the extent and quality of experience that many bring</td>
<td>6</td>
</tr>
<tr>
<td>Better balance between the number of PhD students and post-doc jobs</td>
<td>6</td>
</tr>
<tr>
<td>Funding for small scale, focused biomedical projects, including pilot studies</td>
<td>5</td>
</tr>
<tr>
<td>Improve study design, rigour and the quality of supervision</td>
<td>5</td>
</tr>
<tr>
<td>Health services research, including clinical protocols and guidelines, for improved outcomes for patients, including children</td>
<td>5</td>
</tr>
<tr>
<td>A longer term view of supporting good science rather than short term focus on economic return</td>
<td>5</td>
</tr>
<tr>
<td>PhD clinicians / clinician (physician) scientists, with a career track</td>
<td>4</td>
</tr>
<tr>
<td>Funding decisions should be based more overtly on peer review, e.g. use only reviewers from outside Ireland and none from the same institution as a proposal under consideration</td>
<td>4</td>
</tr>
</tbody>
</table>
Question 12: If you are working in a hospital or other health service setting, please indicate the degree to which you agree or disagree with the following statements. My research has been negatively impacted due to:

- [ ] Lack of a research culture
- [ ] Lack of research support structures
- [ ] Lack of research leadership within the HSE
- [ ] Lack of connections with relevant researchers or industries in my field
- [ ] Lack of protected time for research

Question 13: What, if anything, would you like to change about the current Irish Health Research environment?

**Suggestions made by at least 2 respondents:**

- A culture within health services that values research
- Lift the moratorium (on public sector appointments) to enable more staff so more time for research
- Research on primary prevention
- Research on effective interventions aiming to prevent chronic diseases
- More discussion among academic scientists and industry
- Better opportunities for academic scientists to lead groups that include clinicians.

**Suggestions made by at least 1 respondent:**

- Look at risk especially
- Access to statistical support for researchers within the HSE
- More positive environments in which to conduct clinical research
- Infrastructure support for clinicians and other clinical researchers at CoEs (centres of excellence)
- Job security, defined roles and career structures for research nurses, ie not project-related alone
- A proper EHR [electronic health records] system
• Regional research ethics committees
• More networking structures
• Biobanking of samples to avoid repeat sampling of participants in different studies
• Effective databases and access for researchers
• Unique patient (person) identifier
• Funding for excellent researchers who are not within the priority areas
• Research that makes a difference to people's lives
• Committed funding for translational health research - clinical and laboratory based
• Bursaries should be offered to HSCP's (health and social care professionals) without necessarily requiring leadership from a medical practitioner.
• Funding for service evaluations
• HSE commit a small fraction of its funding for clinical research (e.g. 0.5%)
• Link funding to outputs and outcomes
• An award for 3 years salary funding could be matched 50% by the host institute (thus 4.5 years).
• Make research grant stipends and consumables tax free.
• Funding for early-stage, mid-career and established stages
• Greater collaboration and co-operation across disciplines
• Research embedded as a priority into the emerging regional hospital groups with associated budgets
• Less of a biomedical focus
• Research on the subjective experience of patients / service users
• Use findings from basic scientific research done outside of Ireland and invest in patient-oriented research
• Research on services for children
• Research on health services that provide patient-centred and family-centred care
• Research should be part of all aspects of health
• Cross-disciplinary research
• Career structure/pathway progression, for health services researchers.
• Academic contracts for HSE staff
• Fair access across all locations for HSE staff study leave, e.g. for MSc
• Safeguard jobs for those who take time out to undertake research (PhD especially)
• Start-up funds (2-3 years) for newly appointed staff after which they should be self-funding
• More dissemination of the research that is being done (via a health research website and network);
• Accountability for the dissemination of research done
• Research on Government priorities – findings more likely to be used
• HSE should put into effect results obtained on health services and population health identified by Irish researchers using Irish tax payers money.
• Researchers engage more effectively with policy-makers
• Researchers should be more publicly visible so the line from the development of medical treatments to patient interface with a medical professional is obvious.
• A co-ordinated national strategy for research
• Increased patient interaction in planning and evaluation of research.
• Clinical leadership
• A less simplistic view of the relationship between shiny new devices and improved health outcomes.
• A revisiting of an older social medical view that collective processes, like socio-economic inequalities, more profoundly impact the morbidity and mortality rates in populations than nearly any other measure.
• A HSE Research Directorate
• Cost-effective administration of awards among funders and recipient organisations.

Question 14: Finally, is there anything that you would like to add in relation to any of the questions above or in relation to other topics with relevance to health research in Ireland?

Of the 40 responses to this question, relevant suggestions other than those made to other questions, above, are summarized as follows:
• There is a huge need to develop greater quantitative research capacity within the healthcare system and to encourage quantitative researchers be they engineering, business or mathematicians to work within healthcare research
• More involvement of end users in prioritising research topics and involvement in research projects
• It is great to see the MRCG and HRB collaborate to support patient-centred research.
• The national research priorities ... are industry centred and not patient centred.
• The standard of research in Ireland is generally high, but there are no QA structures to monitor the quality of non-interventional research
• There is no senior data manager/analyst grade. Despite a PhD background, a number of medical research publications and lengthy private sector experience my role in the HSE is only classed as grade VI admin with no possibility of going any higher. Secretarial staff of similar age end up on higher pay by virtue of longer length of HSE service.
• Media involvement and promotion of research projects would be helpful, for example very extensive public media involvement of the Growing up in Ireland study has helped to disseminate that information to the general public. Other health research related to bettering the lives and services of people with or without disabilities should be disseminated in the media.

• Universities should run general classes for non-academic based researchers to access, for example SPSS refreshers or software access when funding is otherwise unavailable (for NVivo software), also institutions (i.e. hospitals/HSE) should be able to share access to software rather than purchasing multiple licenses and extensive cost.

• When applying for a funding please do consider good qualitative methodology projects

• We should consider doing more systematic reviews, national audits, and national research projects.

• Dissemination: among all health care organizations eg: national HIQA conference or national healthcare research conference

• Health research needs to be clearly defined and contextualised. A more holistic approach to health research issues which links both lab, clinic and healthcare infrastructures research together so that all patient issues are addressed. Finding cures and developing treatments are essential, however people continue to live their conditions and need to be supported to do so and developing supportive infrastructure needs to be prioritised in the same way. Having appropriate support services reduces the variables impacting when testing new treatments and would in turn lead to greater success

• It would help if professional bodies mandated a certain amount of professional development to be carried out in order to re-register annually it would go some way to promote research.

• If the grass roots clinicians and nurses etc were incentivised to carry out research it would help.

• Each hospital/ healthcare setting needs an independent person hired to evaluate studies from start to finish. Be a point of contact of advice etc.

• The research environment is improving.

• A strong system could be devised whereby research groups are led by two researchers - one clinical and one scientific, each of whom are equally respected and funded by Irish health research funders. The best research can prevail in such circumstances.

• Health research in Ireland continues to be of a high standard despite recent restrictions on funding - and we should ensure that it remains so by protecting and maintaining available funding where possible.

• Insist that all government departments direct fixed % of budget to research

• Perhaps funding schemes (such as the MRCG/HRB scheme) could prioritise leveraging resources of the smaller (charity) organizations.

• I came back from a... fellowship with ... publications, established a new and successful ... service in a busy teaching hospital, but cannot get funding ... without a past history of a big grant ...
Annex C: Further details on SFI’s centres of interest to the biomedical community

- The INFANT Research Centre - perinatal research centre to enhance detection and management of disorders of pregnancy and early life, e.g. pre-eclampsia, development of diagnostic tests and medical solutions to treat the identified issues.

- The Alimentary Pharmabiotic Research Centre – the study of gut microbia and the links to what people eat, how this effects their health and the development of diagnostic tools, foods and pharmaceuticals to improve health outcomes.

- Solid state pharmaceutical cluster – research in support of the extensive pharmaceutical manufacturing industry in Ireland.

- INSIGHT – connected Health is one of the key areas of study for this BIG DATA Analytics research centre.

- AMBER – applied materials and bioengineering research centre. Studies include the development and use of material in medical devices and how these materials interact at the biological level.

For the near future, there will be greater focus in SFI on funding biomedical science in areas aligned to NRPE Diagnostics, Medical Devices, Food for Health, Connected Health, Therapeutics and Sustainable Food production. Focus areas are likely to change in line with Government policy and with the new SFI remit that includes funding for excellent basic and applied research.

TIDA awards (SFI with EI) involve EIs in the selection of projects in order to optimize success based on marketplace requirements and many are in the biomedical area. The TIDA scheme also has an entrepreneurship training component. There were 70 researchers trained in 2013, providing young researchers with the essential skills to start their business or contribute better to an existing business.
Annex D: Introduction to the Medical Research Charities Group (MRCG) and its members

The Medical Research Charities Group (MRCG) is an umbrella group of medical research and patient support charities. The MRCG represents the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease.

To-date, member charities have contributed €60 million over six years in patient-focused research.

A core belief of the group is that today’s health research is tomorrow’s healthcare. The MRCG vision is that it will provide a sustaining and integrating influence across the medical research community, promoting scientific, clinical and paramedical research. The MRCG believes that patient organisations should lead and stimulate critical medical research needed by patients, and will provide leadership and support to charities in Ireland that are engaged in medical research.

MRCG Member Organisations

The Alpha One Foundation was established in 2001 to promote research into Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improve the diagnosis, treatment, life expectancy and quality of life of people with this inherited condition. www.alpha1.ie

The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland. It is a national voluntary organisation that aims to provide people with all forms of dementia, their families and carers with the necessary support to maximise their quality of life. www.alzheimer.ie

Arthritis Ireland is the only national charity dedicated to improving the quality of life for people of all ages with arthritis. www.arthritisireland.ie

The Asthma Society of Ireland is the charity dedicated to improving the health and well-being of the 470,000 people in Ireland whose lives are affected by asthma. www.asthmasociety.ie

Breakthrough Cancer Research funds the efficient and effective development of new treatments for cancer. We work to significantly impact the number of people who can survive this disease. www.breakthroughcancerresearch.ie

Children’s Fund for Health, Temple Street Hospital was established to raise awareness and funding for projects within Temple Street Children’s University Hospital. They work to to assist it in the purchase of vital equipment and to help establish and fund research to ensure that the best service possible is provided to the children in its care. www.templestreet.ie

COPD Support Ireland supports all those living with chronic obstructive pulmonary disease (COPD), a lung condition that makes it hard for sufferers to breathe due to the obstruction of the airways in their lungs. It brings together local support groups from around the country, to help those living with and caring for someone with COPD. www.copd.ie

Cystic Fibrosis Ireland was set up in 1963 to increase knowledge and awareness of CF and to give advice and support to people with Cystic Fibrosis and their families. www.cfireland.ie

Cystinosis Foundation Ireland is an all volunteer, non-profit organisation dedicated to providing services and support for those in affected by Cystinosis. The Foundation also funds research into the causes and improved treatments of Cystinosis. www.cystinosis.ie

The health research landscape in Ireland: what researchers say

Annex D: Introduction to the MRCG and its members

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DEBRA Ireland is the national charity established in 1988 to provide patient support services and to drive research into treatments and cures for those living with the genetic skin condition, epidermolysis bullosa (EB). www.debraireland.org

Diabetes Ireland Research Alliance is a subsidiary of the Diabetes Federation of Ireland. It was set up to promote Ireland as a knowledge base for global diabetes research and increase the level of diabetes research being undertaken in Ireland. www.diabetes.ie/about-us/what-we-do/research/

Duchenne Ireland The aim of Duchenne Ireland is to raise awareness of Duchenne Muscular Dystrophy at local, national and government level. The organisation raises funds to go directly to the researchers and clinicians who they believe have the best chance of developing improved therapies which will benefit this generation. www.duchenne.ie

Epilepsy Ireland is committed to improving the lives of people with epilepsy in Ireland. Brainwave provides a wide range of services aimed at people with epilepsy, their parents, families and friends as well as raising epilepsy awareness and funding epilepsy research. www.epilepsy.ie

Fighting Blindness funds world-leading research into cures and treatments for blindness. It also provides a unique professional counselling service for people with visual impairments and their families. www.fightingblindness.ie

Friends of the Rotunda was set up to raise funds to finance essential research being undertaken by the Rotunda Hospital. It also supports Voluntary Social Welfare work and continually strives to improves amenities for patients. www.for.ie

Heart Children Ireland The mission of Heart Children Ireland is to enable all children born with Congenital Heart Defects to have the best possible lives. They also aim is to provide practical support for members and to support bereaved families whose children have died from CHD. www.heartchildren.ie

Inclusion Ireland provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to government, statutory bodies, other relevant groups as well as the general public. www.inclusionireland.ie

The Irish Cancer Society aims to improve the lives of those affected by cancer, by providing up to date information and a range of services, by influencing change and raising awareness of cancer issues. www.cancer.ie

The Irish Heart Foundation is the national charity whose mission is to lead in improving the cardiovascular health of people living in Ireland so they do not experience disability or die from preventable heart, stroke and other blood vessel diseases. www.irishheart.ie

The Irish Nephrology Society is comprised of doctors and scientists working in the care of patients with kidney disease, either at a clinical or research level. The mission of the Irish Nephrology Society is to ensure a high quality care for patients with kidney disease by promoting the highest standard of medical practice. www.nephrology.ie

Irish Skin Foundation is an independent charity set up to support people with skin conditions. It brings together three existing organisations - the Psoriasis Association of Ireland, the Irish Eczema Society, and the Melanoma and Skin Cancer Society. www.irishskinfoundation.ie

Irish Thoracic Society is the official society for the broad spectrum of healthcare professionals involved in the care of people with chronic or acute respiratory disease in Ireland www.irishthoracicsociety.com

MS Ireland exists to enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential www.ms-society.ie
Muscular Dystrophy Ireland aims to provide information, advice and support to people with neuromuscular conditions and their families through a range of support services. [www.mdi.ie](http://www.mdi.ie)

Parkinson's Association of Ireland The aim of the Parkinson's Association of Ireland is to assist people with Parkinson's, their families and carers, health professionals and interested others, by offering support, a listening ear, and information on any aspect of living with Parkinson's. [www.parkinsons.ie](http://www.parkinsons.ie)

Raynaud's & Scleroderma Ireland works to help people to live as normal a life as possible, to learn how to cope with Raynaud's and understand their Scleroderma. [www.irishraynauds.com](http://www.irishraynauds.com)

The Research and Education Foundation, Sligo General Hospital is dedicated to the improvement of health and healthcare delivery by promoting the development of a culture of research and education at Sligo General Hospital and in its region. [www.ref-sligo.ie](http://www.ref-sligo.ie)

Royal Victoria Eye and Ear Research Foundation The main function of the Research Foundation is to provide equipment and financial support to staff members at the Royal Victoria Eye and Ear Hospital. It also carries out Research Projects throughout the country for subsequent publication in the literature and presentation at Medical Conferences. [www.rveeh.ie/rveeh/departments/Research_Foundation.html](http://www.rveeh.ie/rveeh/departments/Research_Foundation.html)

Sightsavers International (Ireland) works to combat blindness in developing countries, restoring sight through specialist treatment and eye care. [www.sightsavers.ie](http://www.sightsavers.ie)

The St John of God Research Foundation works to promote and support the development of research strategies in the areas of Intellectual Disability, Adult Mental Health and Child and Adolescent Mental Health, in line with the Order's research mission and national / international developments. [www.sjog.ie](http://www.sjog.ie)

St Patrick’s Hospital Foundation fundraises for mental health services at St. Patrick’s University Hospital and in the community. At the Foundation, we support a vision of a society where all citizens are given the opportunity to live mentally healthy lives. [wwwstpatrickshospitalfoundation.ie](http://wwwstpatrickshospitalfoundation.ie)

St Vincent’s Anaesthesia Foundation is a Charity Trust, set up to support and promote the advancement of education & research in relation to Anaesthesia, Intensive Care & Pain Medicine. [www.sedda.ie](http://www.sedda.ie)

The Children’s Medical and Research Foundation is dedicated to the improvement of children’s health. We invest in outstanding paediatric care and research and support Our Lady’s Children’s Hospital Crumlin and the National Children’s Research Centre. [www.cmrf.org](http://www.cmrf.org)

The Mater Foundation is the official fundraising body of The Mater Misericordiae University Hospital. Funds raised through the Mater Foundation are used to purchase state-of-the-art equipment, enhance facilities and to ensure that all patients at the hospital are cared for in a restful, healing and comfortable environment. [www.materfoundation.ie](http://www.materfoundation.ie)

The Rutland Centre is the largest and most respected private addiction rehabilitation centre in Ireland. Our residential programme is drug free, and we help people transform their lives by providing the highest quality of research based treatment and aftercare services in addiction. [www.rutlandcentre.ie](http://www.rutlandcentre.ie)

The Saoirse Foundation works closely with the medical profession, researchers and other international charities to provide patient support and advocacy and to invest into research into Battens Disease. [www.beeforbattens.org](http://www.beeforbattens.org)
List of Abbreviations

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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>CRF</td>
<td>Clinical Research Facility</td>
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<td>DJEI</td>
<td>Department of Jobs, Enterprise and Innovation</td>
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<td>DoH</td>
<td>Department of Health</td>
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<td>EI</td>
<td>Enterprise Ireland</td>
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<td>EU / EC</td>
<td>European Union / European Commission</td>
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<td>EUPATI</td>
<td>European Patients' Academy on Therapeutic Innovation</td>
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<td>FP7 / FP6</td>
<td>Framework Programme 7 / Framework Programme 6</td>
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<td>HEA</td>
<td>Higher Education Authority</td>
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<td>HRG</td>
<td>Health Research Group</td>
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<td>HRB</td>
<td>Health Research Board</td>
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<td>Health Services Executive</td>
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<td>Health Services Research</td>
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<td>ICE</td>
<td>Interdisciplinary Capacity Enhancement</td>
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<td>ICORG</td>
<td>All Ireland Co-operative Clinical Research Group</td>
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<td>IDA</td>
<td>Industrial Development Authority</td>
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<td>IUA</td>
<td>Irish Universities Association</td>
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<td>IPPOSI</td>
<td>Irish Platform for Patients' Organisations, Science and Industry</td>
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<td>IRC</td>
<td>Irish Research Council</td>
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<td>IRSA</td>
<td>Irish Research Staff Association</td>
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<td>MRCG</td>
<td>Medical Research Charities Group</td>
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<td>NCRC</td>
<td>National Children's Research Centre</td>
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<td>NRPE</td>
<td>National Research Prioritization Exercise</td>
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<td>R&amp;D</td>
<td>Research and Development</td>
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<td>REC</td>
<td>Research Ethics Committee</td>
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<td>SFI</td>
<td>Science Foundation Ireland</td>
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<td>TIDA</td>
<td>Technology Innovation Development Awards</td>
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<td>UCH</td>
<td>University College Hospital</td>
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Professor Bernie Hannigan Biography

Professor Bernie Hannigan is Director of Health and Social Care Research & Development (HSC R&D) and Chief Scientific Advisor to Northern Ireland’s Department of Health, Social Services and Public Safety, a post she has held since 2008 through secondment from the University of Ulster. These roles include strategic oversight and direction of R&D across NI’s HSC Trusts, working in partnership with universities and a range of research funders as well as development of the Healthcare Science professions. Bernie represents NI on many UK and international Boards and Steering Groups that include the Office for Strategic Co-ordination of Health Research (OSCHR), UK Clinical Research Collaboration, National Cancer Research Institute and US-Ireland R&D Partnership.

At Ulster, Bernie continues on a part-time basis as Professor of Immunology. Her previous roles included Pro Vice Chancellor for Research & Innovation and Dean of the Faculty of Life and Health Sciences. Previous Board memberships included InvestNI and the Marine Institute. A native of Dublin, Bernie was educated (BA Mod. Natural Sciences) at Trinity College Dublin and gained PhD (Immunology) from the National University of Ireland, working as Research Assistant in the Royal College of Surgeons in Ireland. She has achieved more than quarter of a century of marriage to a physicist and rearing two sons who shunned science in favour of history.