



## **Medical Research Charities Group (MRCG) response to the Consultation Paper for the Successor to the Strategy for Science, Technology and Innovation**

**March 2015**

### **1. Introduction**

The Medical Research Charities Group (MRCG) welcomes the opportunity to input into the consultation on the successor to the **Strategy for Science, Technology and Innovation**. As an umbrella organisation representing the views of 34 patient groups and research charities (see Annex One) we believe that we are excellently placed to provide considered input into the consultation process.

The MRCG represents the joint interests of charities who actively work to restore health, improve diagnosis and treatment and where possible, prevent disease. This is achieved through investment in medical research and the application of medical research findings. A core belief of the group is that today's health research is tomorrow's healthcare.

The MRCG believe that health research in Ireland needs a renewed vision and commitment that will create a world class health research landscape, providing translatable benefits to patients. We hope that the successor to the Strategy for Science, Technology and Innovation will provide that vision.

In May 2014 the MRCG published the first major study into the health research environment in Ireland as perceived by health researchers, "**The Health Research Landscape in Ireland: What Researchers Say**" (a copy of this report is attached in Annex Two.)

The findings of this report form the basis for our submission.

The key recommendation from that report was the creation of the **Irish Health Research Forum (IHRF): A Single Voice for Research to Improve Health**, which aims to improve the health research environment in Ireland to benefit the health of the public and the care of patients. The IHRF, which the MRCG established in mid-2014, is a partnership of organisations that influence health research in Ireland and allows these bodies to work together to enable high quality research, to support research careers and to promote the involvement of service users. The Forum is led by a Steering Group comprising of representatives of member organisations (see Annex Three.)

## **2. “The Health Research Landscape in Ireland: What Researchers Say” – Objectives & Summary of Findings**

In July 2013, the MRCG commissioned a study to understand better Ireland’s current health research funding landscape from the perspective of researchers. This was the first major study into the health research environment in Ireland as perceived by health researchers. The report was prepared by Professor Bernie Hannigan, of the University of Ulster. (The study methodology for the report is outlined in Section 3.0 of the Report.)

**The objectives of the report were:**

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

The report seeks to provide a snapshot of the evolving health research landscape in Ireland, at a time of considerable change and challenge. The report reflects 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 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. 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.

The emerging findings were further tested through their presentation at a conference in November 2013, attended by over 120 people (See Annex Four for a copy of the Conference Outcome Report.)

### ***Summary of findings on the current research landscape***

Despite Ireland having sustained its strong support for health research throughout the economic crisis a number of issues still remain which were identified in the report:

- **There are gaps in enabling infrastructure for health research, and financial sustainability is a concern.**
- **Particular important areas of research are not prioritised.**
- **Support is focused on the earliest stages of research training and on well-established researchers.**
- **There is limited engagement with potential users of research findings.**
- **The systematic involvement in research of patients or other lay people is not well developed.**
- **The contribution of medical research charities is not recognised in policy documents.**

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

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

- **Enabling Infrastructure:** Progress has been made towards putting in place infrastructure to enable health research however gaps remain and financial sustainability is a concern. According to online survey respondents the primary infrastructure elements that impact negatively on their research are; lack of a relevant patient registry; challenges relating to ethics committees; challenges relating to clinical trial infrastructure; lack of a relevant biobank; lack of legislation to govern the use of patient data; lack of legislation to govern the use of human tissue.
- **Doing research:** Health research funders are selectively funding particular areas of research. Research that is likely to deliver commercial outcomes or that is directly relevant to health services is the most likely to achieve funding.
- **Research Careers:** Support is focused on the earliest stages of research training (for PhD and early post-doctoral) and on established researchers. At other career stages there are disincentives to remaining within Irish health research, both in academia and in clinical careers.
- **Using Research:** Engagement with potential research users is essential to achieve the benefits of research, however, within health services this is limited.

- **Patient Advocacy:** Medical research charities support contact among researchers and patients, however, the systematic involvement in research of patients or other lay people is not well developed.

We will deal with each of these five themes in the context of the SSTI.

### **Theme 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 3.mm)

Survey respondents (Question 10, Annex B of the report) 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%).

## **Theme 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).

### **Theme 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 are, 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)<sup>1</sup>.

Finally, gender-related patterns of researcher careers in Ireland are similar to those elsewhere: a gradual attrition of females during progress towards senior levels.

#### **Theme 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 focussing 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

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<sup>1</sup> Primary Care R&D in Ireland. An external report commissioned by the Health Research Board. 2006. [www.hrb.ie/uploads/tx\\_hrbpublications/PrimaryCareIreland.pdf](http://www.hrb.ie/uploads/tx_hrbpublications/PrimaryCareIreland.pdf)



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 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.

### **Theme 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](http://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.*

### 3. 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.

#### **4. Recommendations from the Report**

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<sup>2</sup>, from the Academy of Medical Sciences, takes a comprehensive view of the sector while the recent publication from the Association of Medical Research Charities<sup>3</sup> puts forward the views of its members.

##### **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

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<sup>2</sup> Reaping the rewards: a vision for UK medical science. Academy of Medical Sciences, UK 2010  
file:///C:/Users/e124346/Downloads/Reaping%20the%20rewards.pdf

<sup>3</sup> Our Vision for Research in the NHS. Association of Medical Research Charities. May 2013.  
www.amrc.org.uk/sites/default/files/doc\_lib/Our%20vision%20for%20research%20in%20the%20NHS.pdf

burden of illness in Ireland. An example of such activity is the UK Health Research Classification System [www.HRCOnline.net](http://www.HRCOnline.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](http://www.lindalliance.org)

(This theme will be addressed at the next Irish Health Research Forum, taking place on 12<sup>th</sup> May 2015 in the Gibson Hotel.)

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 example<sup>4,5</sup>.

As a robust mechanism to realise these developments it was recommended that an **Irish Health Research Forum** (IHRF – [www.ihrf.ie](http://www.ihrf.ie)) be established by the MRCG to contribute to this renewed vision in a forward looking and constructive way by bringing together all the key stakeholders, including patient groups, to engage on a number of levels to:

- **Ensure greater emphasis on the patient perspective in all dimensions of patient research.**
- **Determine strategic and holistic approach to the identification and exploitation of opportunities and obstacles.**
- **Contribute in creating a world class health research environment and improve national health.**

The Forum has already held one meeting in November 2014 on the theme of “Public and Patient Involvement in Research” and the next Forum will be held in May 2015 on the theme “A Process to Prioritise Research Questions for Policy, Practice and Services.”

The MRCG’s members’ have been instrumental in supporting health research in this country, especially through their continued support of the Joint Funding Scheme, run in partnership with the Health Research Board, the aim of the IHRF will be to bring added value to the sector, helping to shape and inform Government policy on health research. It will help to ensure that the health research sector are agile and responsive to new developments, especially at a national policy level. It will also help to contribute to the development of a new vision for Irish Health Research at a macro policy level in a way that is realistic and cognisant of the present economic and policy environment. We are confident that the IHRF will help to address some of the major gaps in the health research environment as identified in our report.

### ***MRCG March 2015***

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<sup>4</sup> INVOLVE strategy: 2012 – 2015. Putting people first in research. National Institute for Health Research (England) [www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEStrategy2012-15.pdf](http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEStrategy2012-15.pdf)

<sup>5</sup> Strategy for Personal and Public Involvement in Health and Social Care research. HSC R&D Division, Public Health Agency, Northern Ireland 2010  
[www.publichealth.hscni.net/sites/default/files/Strategy%20for%20Personal%20and%20Public%20Involvement%20in%20Health%20and%20Social%20Care%20Research.pdf](http://www.publichealth.hscni.net/sites/default/files/Strategy%20for%20Personal%20and%20Public%20Involvement%20in%20Health%20and%20Social%20Care%20Research.pdf)

## ANNEXES

### Annex One

#### About the MRCG

The Medical Research Charities Group (MRCG) is an umbrella group of 35 charities that seeks to generate dynamic medical research in Ireland, driving a greater understanding of how illness can be prevented, how it can be diagnosed earlier and treated more effectively with the ultimate goal of improving the nation's health. Founded in 1998, the goals of the MRCG are to increase funding for medical research, remove the barriers to medical research, increase the profile of medical research in Ireland and provide the services and supports our members require.

**MRCG Members:** Alpha One Foundation, Alzheimer Society of Ireland, Arthritis Ireland Asthma Society of Ireland, Breakthrough Cancer Research, Children's Fund for Health, Temple Street Hospital, COPD Support Ireland, Croí West of Ireland Foundation, Cystic Fibrosis Ireland, Cystinosis Foundation Ireland, DEBRA Ireland, Diabetes Ireland Research Alliance, Duchenne Ireland, Epilepsy Ireland, Fighting Blindness, Friends of the Rotunda, Heart Children Ireland, Inclusion Ireland, Irish Cancer Society, Irish Heart Foundation, Irish Nephrology Society, Irish Thoracic Society, MS Ireland, Muscular Dystrophy Ireland, Parkinson's Association of Ireland, Research & Education Foundation, Sligo General Hospital, Royal Victoria Eye and Ear Research Foundation, St John of God Research Foundation, St Patrick's Hospital Foundation, St Vincent's Anaesthesia Foundation, Children's Medical & Research Foundation, Crumlin Hospital, The Mater Foundation, The Rutland Centre, The Saoirse Foundation.

### Annex Two

***The Health Research Landscape in Ireland: What Researchers Say (See Separate Attachment)***

### Annex Three

#### **Irish Health Research Forum Steering Group Membership Steering Group Members**

Philip Watt (Interim Chair)  
Doug Beaton (HSE)  
Martin O'Donnell (NUIG)  
Eilish McAuliffe (Mater Hospital)  
Eucharía Meehan (Irish Research Council)  
Conor O'Carroll (Consultant)  
Grace Cappock (MRCG)  
Gayle Kenney (Temple St. CUH)  
Ned Costello (IUA)

Rebecca Cramp (IPHA)  
Julie Naughton (IRSA)  
Helen McAvoy (IPH)  
Avril Kennan (DEBRA)  
Mairead O'Driscoll (HRB – Observer)  
Lucy Cusack (Forfás/DJEI – Observer)

#### **Annex Four**

**Outcome Report from the MRCG Conference, November 2013 (See separate attachment.)**