



Medical Research Charities Group Pre-Budget Submission 2012

Today's Health Research | Tomorrow's Healthcare

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1. EXECUTIVE SUMMARY

The Medical Research Charities Group (MRCG) is an umbrella group of 33 charities that seeks to generate a dynamic health 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.

The MRCG now has pleasure in presenting its 2012 pre-Budget submission and case for ensuring priority investment and a well functioning health research infrastructure. This case seeks to show how priority investment for health research delivers patient care, public health service transformation and economic and enterprise development. This case also highlights the need for much improved and more systematic engagement between the HSE and the health research communities and the need to guard against stealth cuts in health research investment.

In preparation for making this submission and in order to strengthen its case, the MRCG recently commissioned research amongst the general public to assess understanding and commitment to health research. The results, which are explored in more detail later in this submission, show that the public sees the value of health research, supports State funding of research and is interesting in participating in health research.

The MRCG will now officially adopt the four priority areas that are outlined in this submission and advocate for their implementation largely through Government and HSE channels, to ensure change in the way that health research is conducted and drive continuous improvements in the nation's health.

2. BACKGROUND

Advances in health research enable more understanding of how illness can be prevented, improvements in the earlier diagnosis and treatment of illness and improvement in the quality of life of people living with illness.

Health researchers working together in a multi-disciplinary manner with highly trained physicians, surgeons and nurses and other healthcare professionals, translate scientific advances in the laboratory into better outcomes for patients. Patients and healthy volunteers, through their participation in clinical studies and the donation of samples for molecular research, also play a key role in health research and make an immense contribution to efforts to understand the mechanisms of disease and improved patient outcomes into the future. The knowledge gained from health research is applied to improve the efficiency and effectiveness of health professionals and the health care system at a national and international level and to improve the health of citizens as a whole.

Overall investment in health research plays a key role in delivering a better healthcare system, is critical to the development of the knowledge economy and contributes to the wider economic gain. Investment creates high calibre research teams which ensure Ireland is seen as an attractive location for overseas investment and private funding. This in turn creates opportunities for spin-off R&D and manufacturing.

Founded in 1998, the Medical Research Charities Group (MRCG) is an umbrella group of health research and patient support charities. The MRCG represent the joint interests of charities specialising in restoring health through research, diagnosis, treatment and the prevention of disease. The MRCG supports patient organisations that lead and stimulate critical health research needed by patients, and provides leadership and support to charities in Ireland that are engaged in health research. A core belief of the group is that today's health research is tomorrow's health care.

The mission of the MRCG is therefore to generate a dynamic health research environment in Ireland. The Group endeavours to achieve this by partnership with external organisations; advocacy to enable change; a forum to promote education and integration; and the provision of direct services to members.

The Health Research Board (HRB) is one of the leading agencies in Ireland supporting and funding health research. It provides funding, maintains health information systems and conducts research linked to national health priorities. Its aim is to improve people's health, build health research capacity and make a significant contribution to Ireland's knowledge economy.

Since 2006 the MRCG has received statutory funding of €1million per annum which has operated through a joint funding scheme with the Health Research Board (HRB) and the MRCG enjoys an excellent working relationship with the HRB. This €1million of funding is matched by €1million of funding from MRCG member charities giving more value for every euro invested by the government. This innovative scheme allows MRCG members to conduct health research where they might otherwise not be in a position to finance the full cost of that research. Crucially, the scheme also allows less experienced researchers to gain appropriate and structured experience and support. To date MRCG members have contributed €60 million over the last six years in patient focused research.

The MRCG understands that this level of statutory funding will be delivered through the HRB in 2012 but it is vital that there is on-going investment by the State into health research. In addition to securing on-going investment, the MRCG wants to operate within a more integrated and focused health research system and so increase the quality and quantity of patient focused healthcare in Ireland. However barriers exist with regard to delivering on this goal. In this 2012 pre-Budget submission, we outline our key focus areas for 2012 in seeking to address and overcome these barriers.

3. PUBLIC UNDERSTANDING AND COMMITMENT TO HEALTH RESEARCH

A key factor in delivering improved healthcare benefits to Irish patients is to establish the country as a global location for health research. To successfully build a world-leading health research infrastructure, it is imperative that the public understand and strongly support health research in Ireland. It is against this backdrop that MRCG commissioned independent market research to ascertain public views on the funding and conduct of health research in Ireland.¹

The participants in the research were asked four questions;

- Who do you think should be leading funder of health research?
- If you were a patient in a hospital and asked to take part in health research, which of the following areas of health research would you be willing to participate in?
- If you were asked to donate money to medical and patient support charities, where would you want the money to be spent?

Statements about the value of health research were also read out to participants and they were asked how strongly they agreed or disagreed with these statements.

The key results from the research were as follows;

- The majority (51%) of the population consider it is the Government who is primarily responsible for funding health research
- 78% of the population agree strongly that health research is important for developing new treatments.
- 54% agree strongly that health research is important for strengthening our reputation abroad.

¹ 1,010 interviews were conducted by Red C (market research agency) by phone using a random digit dial sample to ensure all households, including ex-directory, were covered. Half of the respondents were reached using a RDD (random digit dial) landline sample with the other half using an RDD mobile phone sample. This ensured that 98% of the population were including mobile only households, landline only households and dual phone households. Quotas were set and final data weighted to known profiles on age, gender, class region and phone type to ensure that the sample was representative of the total Irish population aged 18+. The fieldwork was conducted between 14th – 16th November 2011

- 53% agree strongly that the State should maintain its investment in health research during difficult economic times.
- The majority of respondents stated that if asked they would be happy to participate in health research.
- 72% of respondents said that they would donate blood for examination and 55% said that they would donate tissue post surgery for examination. 35% of respondents stated that if asked to donate money to medical and patient support charities, they would want the money spent on health research

4. MEDICAL RESEARCH CHARITIES GROUP (MRCG) POSITION

In 2012, the MRCG's advocacy work will focus on four priority areas:

- Ensuring priority investment for health research to deliver patient care, public health service transformation and economic and enterprise development
- The need for better channels of engagement between the health research community and the HSE
- Maintaining investment in health research and protecting against stealth cuts.
- Maintaining €1m in funding to continue the existing co-funding partnership between the Health Research Board and the MRCG.

4.1 ENSURING PRIORITY INVESTMENT FOR HEALTH RESEARCH TO DELIVER PATIENT CARE, PUBLIC HEALTH SERVICE TRANSFORMATION AND ECONOMIC AND ENTERPRISE DEVELOPMENT

The issue

In an environment that is dynamic and changing, health research in Ireland needs to be positioned where it can make its greatest contribution to patients' welfare, the health system and the economy. We need to move from the current position of valuable but fragmented health research activity to an integrated and focused health research system. Only then will we create the environment where health research can be translated into better public health, improved patient care, a transformed health system and in addition go towards creating the environment needed for health research to flourish.

MRCG priorities

In summary, a well-functioning health research infrastructure encompasses:

- ❖ A coherent and streamlined health research infrastructure to ensure that breakthroughs translate into improvements in human health
- ❖ A primed health system with the capacity to efficiently evaluate, appraise and use the products and services arising from advances in health research
- ❖ Population data that allow us to understand the health needs of the community and the impact of healthcare use on the health of the community.

Against this backdrop, the MRCG:

- ❖ Calls for the filling of the research leader post (Assistant Secretary) in the Department of Health and that health research is a significant part of that post to deliver a health research strategy for Ireland
- ❖ Advocates for appropriate funding for clinical, translational, population health and health services research
- ❖ Supports collaboration between industry, innovators and academia in the development of patient-focused health research
- ❖ Supports sustained investment in Clinical Research Facilities (CRFs) on hospital campuses. A CRF provides the infrastructure, including the physical space, facilities and the experts, needed to support patient-focused research studies.
- ❖ Promotes the development of a pipeline of highly-skilled clinical investigators
- ❖ Supports the establishment of an integrated regulatory and ethics system in Ireland
- ❖ Encourages the analysis of data emerging from population-level surveys, helping to identify the systemic and resource allocation decisions that are needed and future healthcare needs, products and services.

4.2 THE NEED FOR BETTER CHANNELS FOR ENGAGEMENT BETWEEN THE HEALTH RESEARCH COMMUNITY AND THE HSE

The issue

Healthcare practitioners play a vital role in identifying unmet medical needs and giving direction and support to health-related research. However, there is a lack of commitment within the HSE to the embedding of research within the health services.

MRCG priorities

To enhance engagement between the health research community and the HSE, the MRCG:

- ❖ Advocates for a full time Director of Research in the HSE to sit at executive level
- ❖ Advocates for the relevant infrastructure and policies in the HSE to support health research with a national health research system under the aegis of the new Director of Research
- ❖ Advocates for the HSE to take a leadership role in incentivising and supporting clinicians and hospitals to carry out more health research

- ❖ Promotes the value of research activity for the health system
- ❖ Encourages high-level collaboration and the exchange of ideas and practices among Ireland's research community, clinical community and industry
- ❖ Promotes positive health research case studies to enhance Ireland's reputation in health-related research and raise awareness of the impact of health research among health practitioners.

4.3 MAINTAINING INVESTMENT IN HEALTH RESEARCH AND PROTECTING AGAINST STEALTH CUTS

The issue

The OECD average spend on health research as a percentage of GDP is 0.12%, whereas Ireland's spend on health research is just 0.06%, half the OECD average. Spend on health research has come under further pressure as a result of the revised Employment Control Framework (ECF) to universities and institutes of technologies.

Issued by the previous government in its final days, the ECF states that all appointments and promotions, even those financed by overseas funding, private industry or charities must now be channelled through the Higher Education Authority. Any research posts created or any renewal of existing contracts will be subject to an employer's pension contribution charge of 20 per cent of gross pay to the State to protect the State from future pension liabilities. It is estimated that this 20 per cent pension levy will reduce the available amount of core funding for research in State agencies by 15 per cent. This pension levy is certainly not in line with the smart economy agenda. Hidden costs need to be paid for as they amount to a cut in research funding.

MRCG priorities

To protect the national research budget, the MRCG :

- ❖ Requests that all funding for health research projects in State agencies is not impacted by the hidden cut of the pension levy and that available core funding is not reduced.
- ❖ Requests that the quality and quantity of health research being carried out is not impacted by the pension levy.

4.4 MAINTAINING €1M IN FUNDING TO CONTINUE THE EXISTING CO-FUNDING PARTNERSHIP BETWEEN THE HEALTH RESEARCH BOARD AND THE MRCG

The continuation of this scheme will allow MRCG members and the exchequer to leverage philanthropic funding and guarantee better value for each Euro invested. Improved treatments through research will result in long term savings to the economy while increased participation in clinical trials has an immediate effect on increasing the quality of care in the clinical environment. MRCG charities provide employment for approximately 100 researchers driving cutting edge, patient outcome focused research

The Joint Funding Scheme has contributed to the following benefits

- ❖ Co-funding has created high-end career opportunities for many researchers and has been responsible for a number of successful internationally recognised projects
- ❖ It has acted as the catalyst for the funding of research by new charities
- ❖ The existing co-funding scheme has developed a strong partnership between the Health Research Board (HRB) and the MRCG and the reciprocal knowledge and skills acquired through this partnership has created value much greater than the funding itself
- ❖ Patient funded research looks for improved patient outcomes and treatments
- ❖ MRCG charities are skilled in securing philanthropic and private enterprise funding for medical research
- ❖ Co-funding has brought together and added skills to medical charities in research processes .

APPENDIX: Health-Related Research Expenditure in Ireland

Health related research expenditure

'Health-related' research expenditure is defined broadly as 'research which benefits the health of an individual, group or population through the prevention, treatment and management of illness. Such direct interventions include the development of diagnostics, pharmaceuticals, vaccines and devices and the preservation of mental and physical well-being through the services offered by the medical, nursing, and allied health professions. Health-related research may also benefit health through improvement in understanding the mechanisms underlying ill-health (either physical or mental) or the influences and impact of environment (physical, social, cultural or occupational) and behaviour on health status and outcomes.'

The total research expenditure by public and voluntary agencies in 2009 was approx. €567M, of which approx. €215M, or 38%, was on health-related research. The scope and focus of health-related expenditure differs by funding agency and reflects their statutory remit. For some agencies, health-related research is a minor activity (e.g. Environmental Protection Agency, Marine Institute and the Research Councils). For other agencies, health-related research represents a large proportion of their expenditure (e.g. Health Research Board, Department of Health and Children.) Those agencies focus on research that can lead to improvements in disease prevention, health promotion, detection and treatment, training of the next generation of health researchers and on clinical and service delivery improvement. Some agencies support basic and applied biomedical research that may lead to improved understanding, diagnosis and treatment of diseases (e.g. Science Foundation Ireland, Medical Research Charities Group), while others are focused on the exploitation of health-related research findings in the industrial and life sciences section (e.g. Enterprise Ireland, Industrial Development Authority).

Research funding provider - primary focus of health-related expenditure in 2009	Health-related research expenditure 2009	% of total spent on health-related expenditure
	€ 000	%
Prevention, promotion, clinical and service delivery improvement (Health Research Board, Department of Health)	45.368	21
Basic and applied biomedical research (Science Foundation Ireland, MRCG)	83,669	38.9
Infrastructure programmes and post graduate training in university sector (Higher Education Authority, IRCSET, IRCHSS)	40.51	18.8
Sector-relevant research (Environmental Protection Agency, Marine Institute, Department of Agriculture, Food and Fisheries)	7.075	3.2

Research funding provider - primary focus of health-related expenditure in 2009	Health-related research expenditure 2009	% of total spent on health-related expenditure
	€ 000	%
Industrial and Life Sciences Sector (Enterprise Ireland, Industrial Development Authority)	37.68	17.5
TOTAL	215,302	

Health-related research expenditure 2009

It should be noted that the HSE is the health service environment within which most clinical health research occurs. As such the HSE – or more accurately- its health professionals – receive grants from the various funding agencies listed. In effect the HSE does not commission large research projects and does not currently have a dedicated research budget but works in partnership with other agencies.

APPENDIX: MRCG MEMBERS

1. Alpha One Foundation
2. Alzheimer Society of Ireland
3. Arthritis Ireland
4. Asthma Society of Ireland
5. Bee for Batters: The Saoirse Foundation
6. Brainwave: The Irish Epilepsy Association
7. Children's Fund for Health, Children's University Hospital, Temple Street, D1
8. Children's Leukaemia Research Project
9. Children's Medical & Research Foundation, Our Lady's Hospital for Sick Children, Crumlin
10. Cystinosis Foundation Ireland
11. DEBRA Ireland
12. Diabetes Federation of Ireland
13. Duchenne Ireland
14. Fighting Blindness
15. Friends of St Patrick's Hospital
16. Heart Children Ireland
17. Irish Cancer Society
18. Irish Heart Foundation
19. Irish Raynauds' and Scleroderma Society
20. Irish Thoracic Society
21. Meningitis Research Foundation
22. MS Ireland
23. Muscular Dystrophy Ireland
24. Parkinson's Association of Ireland
25. Research & Education Foundation, Sligo General Hospital
26. Royal Victoria Eye and Ear Hospital Foundation
27. Rutland Centre
28. Sightsavers International (Ireland)
29. St John of God Research Foundation
30. St Patrick's Hospital Foundation
31. St Vincent's Anaesthesia Foundation
32. The Cystic Fibrosis Association of Ireland
33. The Mater Foundation

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