# MANIFESTO
# FOR MEDICAL RESEARCH

medical
research
charities
group

*Unity is our Strength*

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## Our Priorities:

- A commitment to increased investment for medical research.
- Appointment of a Director of Research in the HSE and the appointment of a HSE Working Group on access to new and innovative therapies.
- Development and maintenance of patient registries.
- Passing of the Human Tissue Bill and the Health Information & Patient Safety Bill.
- Implementation and resourcing plan, and oversight group for the National Rare Disease Plan.

## Introduction

The MRCG want to ensure there is a dynamic medical research environment in Ireland. Ensuring priority investment for medical research will help to deliver patient care, public health service transformation and economic and enterprise development. A well-functioning medical research infrastructure will ultimately help patients, the health system and the economy.

In this document we present the key priority areas for the members of the MRCG that we are asking political parties to take on board when they are developing party platforms for the General Election and any subsequent Programme for Government.

## Priority 1: Increasing Investment for Medical Research

**Background:** Facilitating and nurturing research in the health system is undoubtedly challenging, especially in a resource-limited environment, but there is a valid case to be made that this is the very time when investment in research can reap dividends. In addition to driving better health outcomes for individuals, communities and populations, investment in health research results in direct cost savings, improved reallocation of resources, objective and concrete data on access, quality, cost and outcomes, improved cost effectiveness and innovative models for the delivery and financing of healthcare.

**Ask: The MRCG believes that health research in Ireland should be a key area of on-going investment, especially during a time of economic constraints, as it assists patients while also benefitting the economy through the creation of jobs and expertise.**

We are a critical player in health research in Ireland. Currently €800,000 in funding is provided annually for health research through the Joint Funding Scheme run by the Health Research Board (HRB). This €800,000 is matched euro for euro in funding from MRCG member charities ensuring huge value for money. This funding allows charities to carry out health research that they would not be able to fund on their own. It also provides valuable opportunities for researchers to gain experience, thereby contributing to the economy.

There needs to be **on-going investment by the State in health research**, in order to improve the care of Irish patients and contribute to the wider economic gain. The Government must not only recognise the importance of investment in this area but also maintain investment in medical research.

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## **Priority 2:** Appointment of a Director of Research in the HSE

**Background:** Research must be embedded in the health system, likewise the health system must be a good place to carry out clinical research and there must be excellent practices and policies to support this.

**Ask:** **The lack of leadership within the health service for the medical research agenda must be urgently addressed. The appointment of a full time Director of Research within the Health Service is particularly needed now for a number of reasons:**

1. To deliver Government policy on health research.
2. To take a leadership role in incentivising and supporting clinicians and hospitals to carry out more medical research and raising awareness of the impact of health research among health practitioners.
3. To promote positive health research case studies to enhance our reputation in this area and to ensure Ireland retains the highest calibre of health researchers going forward.

**Increasing numbers of researchers and academics are choosing to leave Ireland** because of the **lack of investment in research** and the **loss of protected time for research**. These researchers, once they leave Ireland, will bring their expertise, their international research funding and graduate research opportunities with them. This is an extremely worrying situation for us as a small country, the loss of these researchers will have a huge impact on medical research in general, and on patients in particular.

Research and innovation in a primed health system have a vital role in **supporting enterprise development in Ireland**, creating jobs and delivering significant economic benefits to the exchequer through direct and indirect savings. Developing and maintaining a high quality health research system provides opportunities to engage with private enterprises in areas such as pharmaceuticals, medical devices, diagnostics, services science, e-health and assisted living technologies and thereby benefitting the economy.

## **Priority 3:** Improved Support Structures for Medical Research

**Background:** It is vital that there is a **strategy on patient data** and its role in terms of patient research. **Patient Registries** are vital for medical/health research, yet there is no national policy or adequate recognition of the role of patient registries in Ireland. **The work of many patient registries remains undervalued and underfunded.**

**Ask:** **A coherent policy approach for the development and support of patient registries in Ireland.** Patient registries provide vital information on issues such as the number of people suffering from a disease; where treatment centres should be located and whether the survival ages of patients are increasing or decreasing (a key indicator of quality of patient care). Patient registries are recognised internationally as a **vital prerequisite for good quality health research.**

## **Priority 4:** Improved Legislative Framework for Medical Research

**Background:** For there to be a well-functioning **medical research infrastructure** which will benefit patients, the health system and the economy it must be underpinned by an appropriate and proper **legislative framework**. Two key pieces of legislation, the **Human Tissue Bill** and the **Health Information & Patient Safety Bill**, have not received the appropriate attention from successive Governments. The Human Tissue Bill is still a Category C bill while the Health Information & Patient Safety Bill has been a Category B bill since 2009.

**Ask:** **The measures contained in these bills will impact the health research environment in Ireland and contain initiatives which will have major impacts on the areas of population health, registers, the structure and regulation of research ethics approval and regulations for the removal, retention, storage, use and disposal of human tissue.** The fact that neither of these bills has progressed during the lifetime of the current Government is tantamount to institutional failure.

## **Priority 5:** Effective Resourcing of The National Rare Disease Plan for Ireland 2014-2018 (NRDP)

**Background:** In the European Union, a disease is defined as rare when it affects fewer than 5 in 10,000 people. In the EU it is estimated that 6-8% of the population has a rare disease (in Ireland that's around 280-370,000 people.) In other words, up to 1 person in 12 in Ireland may have a rare disease at some stage in their life. **The National Rare Disease Plan for Ireland 2014-2018** (NRDP) was launched by the Minister for Health in July 2014. It was planned to be the first generic policy framework for rare diseases in Ireland. It is broad and it applies to all rare diseases.

**Ask: Clearer commitments on implementing the NRDP and removing uncertainties in key aspects of health policy that impact on rare diseases, in particular:**

- The urgent need for an **Oversight Implementation Group** for the NRDP to be established. This group needs to be formalised and have clear terms of reference.
- The need for the inclusion of the NRDP in the HSE Service Plan for 2016. The lack of visibility and commitment to rare diseases in the **HSE Service Plan for 2015** is a major deficit. The Department of Health is mandated to set out health policy in Ireland, yet it is frustrating and unacceptable that a national plan endorsed by the Minister for Health is not reflected in key HSE planning processes.
- The need for a **Government policy on the future of genetic services in Ireland.** The recent downgrading of the National Centre for Medical Genetics to a Department of Our Lady's Children's Hospital, Crumlin has caused considerable uncertainty for patients. The HSE have indicated that a new plan for national genetic services in Ireland will be drawn up in the near future. MRCG calls on this draft plan to be published as soon as possible along with adequate consultation with key stake holders, including MRCG.
- There is considerable uncertainty in relation to **access to new and innovative drugs** for people with rare diseases in Ireland. The NRDP could play a key role in helping to inform how we approach this complex and sensitive issue in future.



MRCG, Digital Office Centre, 12 Camden Row, Dublin 8, Ireland.
**Telephone:** 353 1 479 3234. **Email:** info@mrcg.ie **Web:** www.mrcg.ie