

Research towards a healthier Ireland

Health Research Charities Ireland
Position Paper 2019

September 2019

hrci.ie



Our health and that of our families and friends is one of the most important things in life.

However, healthcare is only as good as the research behind it.

We need to view research as being integral to care.

Supporting and investing in strong health research in Ireland will ensure better care for Irish patients, a better health system and a stronger economy.

Investing in an improved research environment will have a positive impact across all diseases and health issues in every county of Ireland.

Involving patients and their representatives in the planning and undertaking of research will strengthen its impact.

Funding allocated to health research should be considered an investment rather than a cost.

Summary of recommendations

Recommendation 1 Increase investment in clinical research in Ireland, in line with the recommendations of the CRDI 'Future Investment in Clinical Research' report.

Recommendation 2 Undertake a national information campaign on the value of health research and explaining the importance of patient consent.

Recommendation 3 Establish a National Federation of Patient Registries.

Recommendation 4 Develop a National Genomics Strategy and invest in a public Irish Genome Project.

Recommendation 5 Support a multi-stakeholder, National Engaged Research Hub, through inclusion in national strategies and plans relating to research and development.

About HRCI and its members

Health Research Charities Ireland (HRCI), previously known as the Medical Research Charities Group (MRCG), is the national umbrella organisation of charities active in medical and health research, together representing over 1 million Irish patients. Through support and advocacy, we represent the joint interests of our 37 members, working to improve health and prevent illness through research. We also run the Irish Health Research Forum, bringing together all stakeholders to improve health research in Ireland. It is our core belief that today's health research is tomorrow's healthcare.

Our key activities include

Funding Research

HRCI operates a 'Joint Funding Scheme' in partnership with the Health Research Board (HRB) which, unlike any other scheme in Ireland, is open to all types of health research, for all conditions, including rare and neglected diseases. Currently €900K in funding is allocated annually by the Department of Health to the HRB for the scheme. This is matched by the HRCI member charities, increasing the annual investment in research to up to €1.8 million. 124 research projects have been funded through this scheme since 2006, including [14 new patient-focused research projects in 2018](#).

The fact that research funded through this scheme must be assessed at the standard of the HRB's rigorous processes, helps to ensure that charity-funded research is of excellent quality and funded according to best practice.

Guiding the direction of research

HRCI and our members sit at the interface of the health research community and the general public. We play a very important role in highlighting patient perspectives on research and in ensuring that the patient voice is central to research decision-making. This increases the relevance of health research and helps to ensure impact for patients. HRCI supports its members in their engaged research activities in many ways; for example, through a 'Patient and Public Involvement' (PPI) Shared Learning Group, which facilitates the sharing of information and resources. This has led to multiple initiatives across our member charities, including the establishment of research networks for patients and carers, a guide to developing a PPI strategy and a training toolkit (in development) for members of the public who wish to become involved in research.

Improving the research landscape

The HRCI runs the [Irish Health Research Forum](#) (IHRF), a high-level partnership of organisations and stakeholders working together to influence health research in Ireland. It is the only such initiative in the country. With over 500 members and through its events and reports, we are actively helping to shape health research practice and policy. It allows us to ensure our members and their communities are at the core of national health research discussions and decision making.

The recommendations

In this document we present key priorities for HRCI and our members. We are asking politicians to take them on board in preparation for budget 2020 and in developing party manifestos for the next general election.

These recommendations are based on:

- The views of our members as captured over many years
- The outcomes from Irish Health Research Forum events (run by HRCI)
- Our work with many key stakeholders in health research

The recommendations have been devised not only on the basis of what is important but also what is achievable, and we have focused on areas in which we have observed recent momentum. With political will and partnership among key stakeholders implementing these recommendations has the potential to tangibly improve the health of the Irish public.

1: Increase investment in clinical research

Research undertaken in the clinical setting is in urgent need of additional support and investment and is an area of immense concern for our members. Both the Sláintecare Action Plan 2019¹ and the Department of Health Statement of Strategy, 2016-2019² emphasise the importance of research to support improved healthcare. Evidence from research is absolutely essential for high quality health services. Sometimes this research can be borrowed from other countries but often it is necessary that it be undertaken in the Irish context, in order to ensure that the design of healthcare services, their delivery and their evaluation is undertaken in the best possible way.

Supporting clinical research offers many benefits, including:

- the delivery of better care for patients from healthcare organisations with a strong research culture. This relates to many factors such as improved clinical standards, increased efficiencies and increased staff retention.^{3,4}
- offering Irish patients' earlier access to innovative treatments through clinical trials, than would otherwise be possible.
- Increasing Ireland's attractiveness for the life-sciences industry.

¹ Sláintecare Action Plan, 2019. <https://health.gov.ie/blog/publications/slaintecare-action-plan-2019/>

² Department of Health Statement of Strategy, 2016-2019. <https://health.gov.ie/blog/publications/statement-of-strategy-2016-2019/>

³ Does the engagement of clinicians and organisations in research improve healthcare performance? A three-stage review, 2015, BMJ Open. <https://bmiopen.bmi.com/content/5/12/e009415>

⁴ Organisational benefits of a strong research culture in a health service: a systematic review, 2017, Aust Health Rev. <https://www.ncbi.nlm.nih.gov/pubmed/27074113>

Despite these benefits and their potential to improve the lives of everyone we know, for too long research has been viewed as a 'nice to have' rather than **an essential and integrated aspect of healthcare**. A recent review by the Health Research Board shows that there is significantly less clinical trial activity in Ireland compared to European countries such as Denmark, Norway and Finland.⁵ In a health service beset by too few hospital beds, a lack of staff and recent high-profile crises, research is therefore always put on the back burner, with little thought to its core role in strengthening the health service. It's time for a culture change!

In 2017, a Head of Research and Development was appointed to the HSE which was a very welcome first step and we have engaged very productively with the appointee. However, a much larger, national and coordinated approach will be required in order to make real progress. We were recently involved in an innovative, multi-stakeholder initiative, to assess how we can improve and optimise clinical research, to benefit the population and economy of Ireland. This was led by Clinical Research Development Ireland (CRDI) and resulted in a 2019 *Future Investment in Clinical Research report*⁶, which makes strong recommendations to bring about enhanced clinical research in Ireland and will require investment from both Government and industry. The recommendations, which we fully support the implementation of, include the provision of **'protected time' for research for healthcare professionals**, increased **support for research management and infrastructure within the HSE** and **increased patient and public involvement (PPI)** in clinical research. The full report can be found [here](#).

Recommendation 1. Increase investment in clinical research in Ireland, in line with the recommendations of the CRDI 'Future Investment in Clinical Research' report'

2. Undertake a public information campaign on health research

Awareness levels of the value of health research and what it means to participate in clinical research are low among the Irish population. In parallel, GDPR and the new Health Research Regulations 2018 necessitate a more in-depth patient consent process for research on personal health data than was previously the case. Patients are now being asked to give more time and thought to the consent process, at an earlier stage in their care and at a time when the public is increasingly concerned about the misuse of their personal data. This has the potential to reduce the number of patients participating in research studies. Issues with the recruitment of patients, is already one of the biggest barriers faced by clinical trials⁷, resulting in increased timelines,

⁵ **Review of clinical research infrastructure in Ireland**, 2019. Health Research Board. https://www.hrb.ie/fileadmin/2_Plugin_related_files/Publications/2019_Publication_files/Review_of_clinical_research_infrastructure_in_Ireland.pdf

⁶ **Future Investment in Clinical Research report**, Clinical Research Development Ireland, 2019. <https://crdi.ie/future-resourcing-of-clinical-research/>

⁷ **Clinical Trials, can technology solve the problem of low recruitment?** 2011, British Medical Journal. <https://www.bmj.com/content/342/bmj.d3662>.

costs and often risking their success. If the public do not understand the value of research and how their sensitive data is protected, they are less likely to give their consent.

A national information campaign to inform the public about clinical research, encouraging them to ask their doctors about research and to explain the consent process and other research safeguards, should be undertaken. This was one of 10 recommendations to result from a 2018 Irish Health Research Forum event on GDPR and health research.⁸ The need to ‘emphasise potential health benefits of research studies and health-care initiatives on future generations and other disease areas, as an incentive for wider participation in data sharing initiatives’ was also recommended by a recent publication on a based on a European survey of 2,013 rare diseases patients and family members.⁹

Such a campaign would offer many additional benefits, including helping to restore faith in the health service and increasing support for medical and health research charities.

Recommendation 2. Undertake a national information campaign on the value of health research and explaining the importance of patient consent.

3. Invest in patient registries

The capturing and use of important health data through patient registries is broadly recognised as a critical underpinning for improving healthcare.¹⁰ For many of HRCI’s members, patient registries are a priority, in order to enable the capturing of information on the demographics of patient populations, the facilitation of patient access to clinical trials and the enablement of broader research. For rare diseases, some of which are more common in Ireland than other parts of the world, these needs are intensified.

Although examples of good practice exist, the current health information technology infrastructure in Ireland is highly fragmented with major gaps and silos of data, making decision-making a challenge for those planning health and social services. There were just 75 national health data collections recorded in Ireland in 2017.¹¹

To compound the issue, the patient registries that exist are under-resourced in terms of funding, time and expertise. There are currently no funding streams in Ireland to support the development or maintenance of registries and expertise in registries is limited. There is also no national policy or adequate recognition of their role.

⁸ **GDPR and Health Research: Stakeholder Voices. Irish Health Research Forum Report and Recommendations**, 2018, Irish Health Research Forum. <http://bit.ly/DataProtectReport>

⁹ **Share and protect our health data: an evidence-based approach to rare disease patients’ perspectives on data sharing and data protection - quantitative survey and recommendations**, 2019, Courbier et al. Orphanet Journal of Rare Diseases. <https://ojrd.biomedcentral.com/articles/10.1186/s13023-019-1123-4>

¹⁰ **Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review**, 2017, PLoS One. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5591016/>

¹¹ **Catalogue of National Health and Social Care Data Collections**, 2017, Health and Information Quality Authority. <https://www.hiqa.ie/reports-and-publications/health-information/catalogue-national-health-and-social-care-data>

HRCI published a guide to developing patient registries in 2018 and offered a vision for the future of patient registries in Ireland.¹² Central to that vision is increased collaboration and the sharing of resources between registries. This could be achieved through support for an independent National Federation of Registries, acting as a trusted third party to support current registries and facilitate the development of new ones. Planning for such a Federation should be central to the Department of Health's Health Information System (HIS) Strategy for the Irish healthcare system, currently in development. The coming together of patient registries under one umbrella would facilitate increased collaboration, the sharing of resources and the establishment of registry standards.

Recommendation 3. Establish a National Federation of Patient Registries.

4: Initiate a public genome project

The genome refers to the 20,000 or so genes we each have. It is what makes us who we are. It is responsible for how we look and for our personality to a large degree. It is also responsible for genetic diseases and a contributing factor in illnesses that have multiple underlying causes.

When you consider the combined genomes of the Irish population, together they offer an incredible wealth of data. Data is now sometimes referred to as the 'new oil' and nowhere is this more true than in the case of genomic data from a large population of people. The most obvious use for this valuable data is in healthcare innovation.

Genomic research on all forms of human genetic disease, from cancer, to rare single-gene conditions like cystic fibrosis, to complex conditions with many causes like multiple sclerosis, is pointing the way to better and a more personal approach to medicine. Giving the right medicines to the right people, at the right time will make the health service more cost effective. In 2018, an Academy of the UK's leading medical scientists predicted that genomics was one of the key areas with the most potential to transform society by 2048. They suggest that it will become a 'first-line technology' for healthcare within the next 30 years.¹³

However, with the exception of some pockets of excellence, the Irish health service has been very slow to use the power of genomic data and research to inform its clinical decision-making. This contrasts with the UK where great advances are being made in genomic medicine and research through public funding.¹⁴

There has been state investment, on a commercial basis, in a genomics company operating in

¹² **Developing a patient registry: a practical guide**, 2018, The Medical Research Charities Group.
<http://bit.ly/PatRegGuide>

¹³ **Horizon Scanning – research and innovation to transform the health of society by 2048**, 2019, The Academy of Medical Sciences. <https://acmedsci.ac.uk/more/news/academy-horizon-scanning-report-published>

¹⁴ **UK DNA project hits major milestones with 100,000 genomes sequenced**, 2018, New Scientist.
<https://www.newscientist.com/article/2187499-uk-dna-project-hits-major-milestone-with-100000-genomes-sequenced/>

Ireland and, while it remains to be seen, there may yet be a role for this company in strengthening Irish health research and the health service, through the data they are collecting on the Irish public. However, it would be a huge mistake to presume that this is all that is required in order to cater for the increasing need for genomics research to be a part of the healthcare of the Irish population.

A **national genomics strategy**, developed with the involvement of all key stakeholders, including patient representatives, is required as a matter of urgency. Central to this should be investment in a **public genome project** which makes Irish genomic data freely available for research and to guide healthcare. This has the potential to be among the greatest investments the state could make.

Recommendation 4. Develop a National Genomics Strategy and invest in a public Irish Genome Project.

5: Facilitate patient and public involvement in all forms of research decision-making

For too long health research was undertaken without the simple act of asking patients and the public what they wanted from it. However, engaged research or, as it is more commonly referred to across the health sphere, patient and public involvement (PPI), is fast becoming the norm in health research. It refers to the involvement of patients, carers and the public, not just as research subjects but as decision makers in the research process. While it brings many challenges, done in a meaningful way it can improve the quality, relevance, timeliness and impact for patients and wider society from research.¹⁵

Patient-focused organisations have long played a role in acting as a lynchpin between the patients they represent and the research community and, by their very nature, they often represent a very tangible form of PPI. In Ireland, the role of medical and health research charities, in the broad sphere of health research, is evolving and growing in importance. They are central to educating and involving patients in research, in tackling the many barriers between the 'bench and the bedside' and in ensuring that the outcomes of research are effectively translated into patient and societal benefit. This is evidenced by the fact that the HRCI/HRB Joint Funding Scheme (outlined in the introduction) demonstrates the highest productivity of all HRB funding schemes with regards to healthcare innovation and policy and practice outputs.¹⁶

A survey we undertook in 2018 (unpublished) indicated that most of our members are very active in engaging their communities in research planning and decision-making. However, the results also demonstrated that not one of the 19 charities who responded have a dedicated

¹⁵ **Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis**, 2018 British Medical Journal. <https://www.bmj.com/content/363/bmj.k4738>

¹⁶ **Outputs and outcomes of HRB awards completed in 2014 and 2015**, 2017, Health Research Board. <https://www.hrb.ie/funding/evaluation/evaluation-reports/publication/outputs-and-outcomes-of-hrb-awards-completed-in-2014-and-2015/returnPage/1/>

budget or allocated time for such activities. This means that the engagement that is vital to impactful PPI is left to chance. While there has been some investment at a national level in supporting engaged research/PPI in higher education institutes (e.g. Campus Engage and the Health Research Board – Irish Research Council’s PPI Ignite initiatives) this has not been matched by investment in the community and voluntary sector, despite the fact that it is obviously essential they be an equal partner in any engaged research initiatives. Such lack of investment contributes to the fact that only one in four EU-funded collaborative research projects, funded through FP7, involved civil society organisations, despite the EU encouraging their involvement and despite the potential for funding.¹⁷ In short, our failure to invest in CSO engagement is also constraining Ireland’s capacity to attract high value EU research funding.

Equally, until lately, there has been no leadership in bringing together all engaged research stakeholders at a national level. This was identified as an issue in a 2016 Campus Engage report, which stated that the ‘**lack of national coordinating structures is constraining effective collaboration and exploitation of synergies within and across higher education institutions, and wider societal interests. These structures and associated leadership already exist for industry engagement and are addressed by Enterprise Ireland and Knowledge Transfer Ireland: a similar service for societal innovation needs to be provided.**’¹⁸

In response to the overwhelming need for the development of a national resource for engaged research in Ireland, a nascent **National Engaged Research Hub** has recently been established as a partnership between Campus Engage, The Wheel, PPI Ignite TCD, the HRCI and with the likely inclusion of additional groups over time. This Hub has enormous potential to enable Ireland to address societal challenges through research. By ensuring that all perspectives are brought to the table, it will bring Ireland’s capacity to design and deliver engaged research to another level. As a small, well-connected country we believe that this cross-sectoral approach will be an achievable and effective way to overcome the challenges identified and will position Ireland as an international leader in this area.

To develop and succeed however, the Engaged Research Hub will need to be appropriately resourced and will need strong participation from the public authorities in order to deliver this successful cross-sectoral approach.

While Innovation 2020 tentatively endorsed the involvement of civil society in research, the next Irish strategy for research and development, should place engaged research at the heart of its plans. A key action should be to support a multi-stakeholder, National Engaged Research Hub. This would establish Ireland as a global leader in tackling the grand societal challenges of our time, aligned with the Sustainable Development Goals¹⁹ and with the mission-based focus of Horizon Europe.

¹⁷ consider-project.eu, 2015

¹⁸ **Engaged Research, Society and Higher Education Addressing Grand Societal Challenges Together**, 2016, Campus Engage. <http://www.campusengage.ie/what-we-do/publications/>

¹⁹ **17 goals to transform our world**, Government of Ireland. <https://irelandsdq.geohive.ie/>

In the words of President Higgins,

‘Universities are both apart from and a part of society. They are apart in the sense that they provide a critically important space for grasping the world as it is and – importantly – for re-imagining the world as it ought to be. But Universities are also a part of our societies. What’s the point unless the accumulated knowledge, insight and vision are put at the service of the community? With the privilege to pursue knowledge comes the civic responsibility to engage and put that knowledge to work in the service of humanity’.²⁰

Recommendation 5. Support a multi-stakeholder, National Engaged Research Hub.

²⁰ President Higgins speaking at the launch of the Irish Centre for Autism and Neurodevelopmental Research, 2012, Galway.



Health Research Charities Ireland (HRCI)

Digital office Centre

12 Camden row, Dublin 8, Ireland

T 353 1 479 3234

E avril@hrci.ie

www.hrci.ie

The HRCI is supported by



Rialtas na hÉireann
Government of Ireland

