

# Position Paper 2024

Health Research Charities Ireland

*Three recommendations for elected representatives &  
policy makers*

[www.hrci.ie](http://www.hrci.ie)



***Research is the essential foundation of modern medicine and healthcare***

***Investment in research infrastructure and supports is an investment in every person in Ireland***

***New legislation in key areas can improve the regulation, transparency and effectiveness of health research***

***Health research charities are responding directly to the needs of the public and accelerating impact from research***

## **Summary of recommendations**

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|-------------------------|------------------------------------------------------------------------------------------------|
| <b>Recommendation 1</b> | Increase capital expenditure in health research                                                |
| <b>Recommendation 2</b> | Progress health research legislative reform                                                    |
| <b>Recommendation 3</b> | Include health research charities and wider civil society in national research decision making |

# About HRCI and our members

Health Research Charities Ireland (HRCI) is the national umbrella organisation of over 45 charities active in health, medical and social care research, together representing more than 2 million people in Ireland. We champion our members' interests, to enhance the environment for health research in Ireland. We empower them to realise our shared vision of improving lives through impactful research. [See our members here](#). Our key activities include:

## **Empowering our members in their research activities**

At the core of our purpose is the commitment to empower and support our member organisations in their health research activities. We do this in many ways, but key amongst them is by fostering a sense of community, in which support can come from many places. We will also demonstrate leadership, by remaining well-versed and engaged in the health research environment, in order to keep our members informed and prepared.

## **Facilitating excellent research through the HRCI-HRB Joint Funding Scheme**

We run a 'Joint Funding Scheme' in partnership with the Health Research Board (HRB), through which our members can secure matched funding for research aimed at addressing the needs of their communities. To date, 151 awards have been made, representing a total investment of €25 million.

## **Strengthening PPI and the involvement of our members in health research**

We and our members serve as a crucial link between the realms of science and society. We support our members as they involve their communities in their research decision-making and as they facilitate researchers to undertake public and patient involvement (PPI). We also work to highlight the value and perspectives of our members and we amplify our efforts through partnerships with other PPI focused groups.

## **Positively influencing Ireland's health research landscape**

As the collective voice of our members, we recognise our responsibility to improve the Irish health research environment. As an independent and disease/condition-agnostic organisation, with a strong patient/public focus we are well-positioned to make a difference. In particular, through running the Irish Health Research Forum, we bring together all stakeholders to positively influence health research in Ireland, to the ultimate benefit of patients and the public.



# The context

## Health research charities shaping research

As an umbrella organisation for over 45 charities who invest in and support research, we see the immensely important role that these organisations play in improving human health and well-being. Together, they invested more than €18 million in health research in 2021. In 2022 they funded 19 new patient and public-focused<sup>1</sup> projects through the HRCI-HRB Joint Funding Scheme<sup>2</sup>.

Beyond financial investment, they ensure that research is meaningful and impactful to the communities they represent. In a 2022 HRCI survey over 80% reported that they are active in each of the following areas: funding research, supporting patient and public involvement (PPI), connecting research stakeholders, communicating the results of research to lay audiences and using research outcomes to bring about patient/public benefit. In a 2023 HRCI survey, our members reported spending an average of 16 hours per month on PPI, dedicated to supporting their communities to be involved in a range of research activities.

Together these charities provide a beautiful example of what research means to people and families and how its impact reaches every village in Ireland.

## National progress in 2023

Some progress was made throughout 2023, towards putting health research at the heart of society. Much of it addresses topics which were the focus of previous HRCI recommendations. Included in the markers of that progress were:

- Progress was made on the **Health Information Bill**, in parallel with planning for the European Health Data Space Regulation.
- The general scheme of the **Research and Innovation Bill 2023** was published, which provides for a new statutory body, Taighde Éireann-Research Ireland.
- The **HSE National Policy for Consent in Health and Social Care Research** was published.
- The Department of Health published a **Statement of Priorities in Health and Social Care Research 2023-2025**.
- The HRB launched a proof-of-concept report, developed by the Irish Centre for High End Computing, focused on **Data Access, Storage, Sharing and Linkage (DASSL)**, to support research and innovation in Ireland.
- The **HSE Regional Areas Implementation Plan** was published, and it notes the importance of research ethical oversight, governance, management, and support services being embedded in the health regions.

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<sup>1</sup> Please note that the term patient is not a perfect fit for all our members, but we are using it broadly to refer to patients, carers, service users, everyone affected by a health condition/concern or members of the public involved in or who might be impacted by health research.

<sup>2</sup> <https://hrci.ie/joint-funding-open-calls/>

- An event entitled **Academic Health Science Systems: The Foundation of Sláintecare** mobilised support for embedding research and education at the heart of healthcare.
- The Evidence for Policy Unit within the Department of Further, Higher Education, Research, Innovation and Science (DFHERIS) undertook a consultation with researchers towards a **higher education research-policy engagement framework**.
- The **National PPI Ignite Network** reached the half-way point of its current phase and received strong endorsement from its funders, the Health Research Board (HRB) and the Irish Research Council to continue in its work.
- Progress was made in implementing the **National Strategy for Accelerating Genetic and Genomic Medicine in Ireland** and in consolidating Ireland's involvement in the European **1+ Million Genomes** initiative.
- The Government announced the development of a new **Rare Disease Strategy**, which will include a focus on research.
- HRCI held two **Irish Health Research Forum** events, on research ethics and on biobanking in Ireland.

## Looking to 2024

Despite recent progress, it is clear that many aspects of health research are in urgent need of attention and support. In this context, we present the 2024 priority recommendations for HRCI and our members. We are asking elected representatives, policy makers and everyone with influence in the health research space to prioritise them, as they plan for the year ahead.

# Developing the recommendations

Through our regular meetings with our highly informed member charities, themes around health research emerge, recur and evolve. As a community, we continually refine our knowledge of patient and public needs, the potential of research and the barriers to progress.

The three recommendations below are based on:

- The views of our Board and members, captured through surveys and regular meetings.
- The outcomes of Irish Health Research Forum events (run by HRCI).<sup>3</sup>
- Guidance from our multi-stakeholder Irish Health Research Forum Steering Group.<sup>4</sup>
- Our on-going engagement and collaboration with all key stakeholders in health research.

The recommendations have been crafted with consideration for what is most urgently required in the system and what elected representatives and policy makers have the power to influence. Those interested should also look to our earlier position papers which address both overlapping and distinct needs, many of which have yet to be sufficiently addressed.<sup>5</sup>

The implementation of the recommendations holds the potential to significantly enhance the health of the Irish public. **We stand ready to provide any additional information required and to support any activities in response to our recommendations.**

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<sup>3</sup> <https://hrci.ie/irish-health-research-forum/irish-health-research-forum-reports/>

<sup>4</sup> <https://hrci.ie/irish-health-research-forum/steering-group/>

<sup>5</sup> <https://hrci.ie/publications/advocacy-documents/>

## Recommendation 1: Increase capital expenditure in health research

Investing in health research and its associated supporting structures is a commitment to the well-being of the population, the advancement of medicine and care, and the overall prosperity of our society. It is instrumental to improving health outcomes, fostering innovation, and addressing global health challenges. Through the **Creating Our Future initiative**, the public made it clear that they want better healthcare and the incorporation of research into the healthcare system.<sup>6</sup> **Impact 2030**, Ireland's Research and Innovation Strategy, states *'It is not possible to envisage a high-performing health service without health research and innovation being embedded in service delivery, and clinicians and other health professionals being supported to undertake and utilise research'*.<sup>7</sup> The **Programme for Government** commits to *'promoting research and, in particular clinical trials, which are key to improving the prevention, diagnosis and treatment of rare diseases.'*

Ireland is fifth from bottom in the table of 31 OECD countries, with regards to Government investment in research and development.<sup>8</sup> Our investment of 0.29% of GDP is well below the OECD average of 0.60% and very substantially below the EU member states average of 0.71%. Despite this, Government R&D expenditure as a percentage of all expenditure has not increased since 2011. For the public, health is a clear priority, yet only 13.9% of the total R&D budget is directed at research intended to improve health, and the HRB's budget made up only 5% of the total in 2022.<sup>8</sup>

Long-term capital investment in health research is particularly required, to ensure value from State-funded research projects and programmes and to strengthen the health research environment. While the HRB commendably supports clinical research through various mechanisms, a review indicates a notable disparity in clinical trial activity compared to European counterparts such as Denmark, Norway, and Finland.<sup>9</sup> More widely, the HRB's constrained budgets do not permit the necessary capital expenditure in wider infrastructure. The HSE, despite being a hub for substantial research, grapples with severe underinvestment in R&D, a situation exacerbated by persistent overspends in healthcare and staffing embargoes. In this regard the UK's sizable and persistent support of clinical research provides a model to look to.<sup>10</sup>

The health research community consistently reports being hampered by the lack of necessary supports and being trapped in a cycle of constant concern about sustainability. Over the last four years of the Irish Health Research Forum, a resounding plea from the hundreds of diverse attendees has been for more capital expenditure in research infrastructure.<sup>11</sup> There have been particular calls around digital health, clinical research infrastructure, research ethics committees, biobanks, patient registries and PPI supports.

Clear and coordinated avenues of investment are urgently required. A substantial increase in the HRB budget is necessary. The **HSE National Framework for Governance, Management and Support of Health Research**<sup>12</sup> provides a roadmap for improvements in the HSE, including plans for regional research support functions but it needs support and investment. The Department of Health, DFHERIS and the new agency Taighde Éireann-Research Ireland all have a role to play too. A concerted effort across these entities is paramount.

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<sup>6</sup> <https://creatingourfuture.ie/wp-content/uploads/2022/07/Creating-Our-Future-EXPERT-Report.pdf>

<sup>7</sup> <https://www.gov.ie/en/publication/27c78-impact-2030-irelands-new-research-and-innovation-strategy/>

<sup>8</sup> <https://www.gov.ie/en/publication/16c4d-the-research-and-development-budget-2022-to-2023/>

<sup>9</sup> <https://www.hrb.ie/publications/publication/review-of-clinical-research-infrastructure-in-ireland/returnPage/4/>

<sup>10</sup> <https://sites.google.com/nih.ac.uk/thefutureofukclinicalresearch/home?authuser=0>

<sup>11</sup> <https://hrci.ie/irish-health-research-forum/irish-health-research-forum-reports/>

<sup>12</sup> <https://hseresearch.ie/governance-framework/>



## Recommendation 2: Progress health research legislative reform

### Prioritise the National Research Ethics Committees Bill

Dedicated individuals in Ireland are working tirelessly to uphold the highest standards in research ethics, often in challenging circumstances and usually on a voluntary basis. Despite their efforts, the existing systems are fragmented and under-resourced, leading to delays in research. This situation hampers the potential of health and social care research to have a tangible impact on people's lives. A pivotal recommendation from an **Irish Health Research Forum event in May 2023** was that *'The Department of Health should enable through legislation a coordinated approach to providing single ethics opinions for multi-site research studies which are not currently covered by the National Research Ethics Committees'*.

In 2019 the government approved the General Scheme of the **National Research Ethics Committees Bill** for formal drafting. However, progress has since stalled.<sup>13</sup> This legislation is an important enabler in reforming the research ethics committee framework for health research in Ireland. Certain aspects addressed by the Bill have seen progress, such as the establishment of some National Research Ethics Committees (NRECs), and a National Office to drive and support the reforms. The initial NRECs operate on a statutory basis through amendments to existing statutory instruments (secondary legislation), allowing Ireland to meet its obligations under EU regulations for clinical trials and medical devices.<sup>14</sup> The National Research Ethics Committee Bill must be enacted to provide a legislative footing for NRECs to be established in other areas of health research, such as genomics studies and patient registries. It is an essential element of streamlining the system, reducing duplication of effort, and strengthening the quality of research ethics processes in Ireland.

### Develop biobanking legislation

Biobanks are a backbone in the advancement of medicine through scientific discovery. The study of human tissue samples, including blood, skin, DNA and associated patient information, provides crucial insights for understanding and treating medical conditions. Underscoring this, the UK biobank is considered by many to be the world's most important health database.<sup>15</sup> However, managing a biobank in Ireland comes with huge challenges. At a **November 2023 Irish Health Research Forum event** focused on biobanks, participants expressed frustrations stemming from inadequate support (event report to be published in April 2024). These challenges hinder their ability to operate at optimal levels, impeding their potential to make a meaningful impact on patient outcomes.

To address these issues effectively, legislation is imperative to regulate the collection, storage, and utilisation of human biological samples and associated data for research purposes. It's noteworthy that the existing Human Tissue Bill 2022 does not adequately cover these aspects. Enacting such legislation is essential to ensure ethical and transparent practices in biobanking which will foster public trust in the responsible use of human biological samples for research purposes. Several European countries, including Belgium, Estonia, Finland, Hungary, Latvia, Lithuania, Portugal, Spain, Sweden, and the UK, have specific biobanking legislation, providing valuable models for Ireland to consider<sup>16</sup>, and Scotland made an amendment to its Human Tissue Act, to allow for the use of biomaterial for research<sup>17</sup>.

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<sup>13</sup> <https://www.oireachtas.ie/en/debates/question/2023-07-25/1180/?highlight%5B0%5D=research&highlight%5B1%5D=ethics>

<sup>14</sup> <https://www.nrecoffice.ie/about/legislation/>

<sup>15</sup> <https://www.theguardian.com/science/2023/nov/30/uk-biobank-and-the-masses-of-medical-data-that-became-key-to-genetic-research>

<sup>16</sup> <https://link.springer.com/content/pdf/10.1007/978-3-030-49388-2.pdf>

<sup>17</sup> <https://www.legislation.gov.uk/asp/2006/4/contents>



## Recommendation 3: Include health research charities and wider civil society in national research decision-making

An aim to put research and innovation at the heart of addressing Ireland's challenges is stated in **Impact 2030: Ireland's Research and Innovation Strategy**.<sup>18</sup> It also expresses a goal to foster public engagement in the research process by building upon the work of the **Creating Our Future** campaign.<sup>19</sup> The report from this initiative highlighted that the public want to see research embedded within the healthcare system in Ireland and for public and patient participation and engagement in health research to be central to that. Significant strides have been taken in this regard by the HRB and the noteworthy progress achieved by the PPI Ignite Network is particularly commendable. While there is more to be done, the HSE and the Department of Health have also taken early steps to improve the involvement of patients and the public. However, other Government departments and agencies have yet to follow suit in embedding civil society perspectives in decision-making and initiatives. For example, the recent process to appoint the Board of Taighde Eireann–Research Ireland specified that one member must bring an enterprise perspective but there was no equivalent position dedicated to a societal perspective. In general, charitable funders are not included as consistent participants in governmental or inter-agency research funding conversations.

The 45+ HRCI member charities invested more than €18 million in research in 2021. Notably it has been calculated that in the UK, for every £1 invested in research from public and charitable sources, between 25p and 28p is returned to the economy each year, on an on-going basis.<sup>20</sup> Beyond financial investment, charities ensure the relevance of research to the communities they represent, communicate its findings and insist that it has impact for people. Their role in research is wide-ranging and cannot be replicated by other funders. A new HRCI-PPI Ignite Network guide highlights the value of charities in research partners.<sup>21</sup>

Internationally, stronger inclusion of charities as significant players in research can be witnessed. For example, charities and community organisations (including Irish representatives) are actively involved in an international 'Ensuring Value in Research Funders Forum'.<sup>22</sup> In the UK, the medical research charities are recognised as a key pillar of their world-leading life sciences sector and involved accordingly.<sup>23</sup>

The Evidence for Policy function that sits in DFHERIS, aims to improve the articulation of public policy needs to researchers. As those often closest to the needs of the public, charities and civil society organisations also have an essential perspective on this. DFHERIS has made progress on the Open Research agenda and, again, charities are very well-positioned to support its ultimate aim to ensure impact from research. Charities also bring much expertise on equality, diversity and inclusion (EDI) which is highlighted by Impact 2023 as being important in among researchers but must also extend to research participants and to research policy making.

We would welcome concrete action on the stated intention in Impact 2030 to widen participation in engaged research beyond the traditional partners of industry and academia. Charities are ready to embrace opportunities to be involved.

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<sup>18</sup> <https://www.gov.ie/en/publication/27c78-impact-2030-irelands-new-research-and-innovation-strategy/>

<sup>19</sup> <https://creatingourfuture.ie/wp-content/uploads/2022/07/Creating-Our-Future-EXPERT-Report.pdf>

<sup>20</sup> <https://fraserofallander.org/wp-content/uploads/2022/03/FAI-The-contribution-of-medical-funding-by-charities-to-the-UK-economy-1.pdf>

<sup>21</sup> <https://hrci.ie/hrci-ppi-ignite-network-charities-researchers-partnering-guide/>

<sup>22</sup> <https://evir.org/membership/>

<sup>23</sup> <https://twitter.com/NMRPerrin/status/1729411446432272723>

# Finally

We appreciate you taking the time to read our 2024 position paper. We are always open to questions, and we welcome engagement, so please don't hesitate to get in touch. Our contact details are listed below.

For other organisations undertaking advocacy in health research, we have a strong belief in the power of sharing and collaboration, and so we encourage you to adopt these recommendations in your own advocacy campaigns.



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