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## HRCI strategy 2024-2027

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# **HRCI Strategy**

**2024 – 2027**



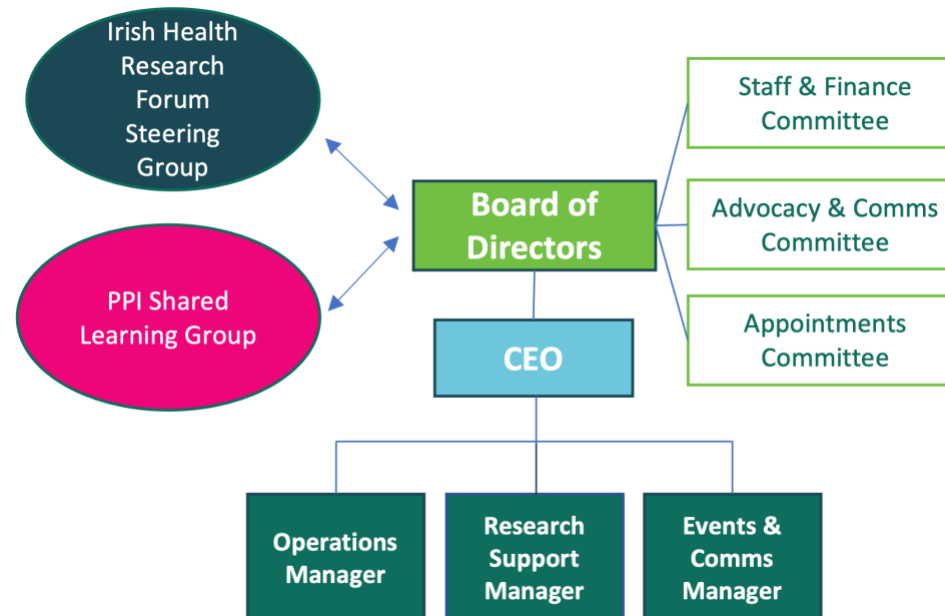
## About HRCI and our members

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities engaged in health, medical and social care research, collectively representing over 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.

We offer our members the potential for matched research funding through the Joint Funding Scheme, run in partnership with the Health Research Board. We also run the Irish Health Research Forum bringing together all stakeholders to improve health research in Ireland.

Our 45+ member charities invested more than €18 million in research in 2021 alone. Beyond financial investment, they ensure the relevance of research to the communities they represent, communicate its findings and insist that it has impact for people. Together these charities provide a beautiful example of what research means to people and families and how the impact of research reaches every village in Ireland. Please see our website for our current list of members: <https://hrci.ie/our-members/>

### HRCI Organisation Chart



## The top 20 impacts emerging from our previous strategy

Our 2020 – 2023 strategy served us very well and led to numerous impacts. Many of our activities will be continued and built upon in our new strategy.

1. **Facilitating research funding:** 29 more projects funded through the HRCI-HRB Joint Funding Scheme, resulting in a cumulative investment of €25 million to date. Organised 2 events to celebrate the successes, one opened by the Minister for Health.
2. **Offering national leadership:** Organised 7 Irish Health Research Forum events focusing on topics such as genomics; research in the health service; research impact; research ethics processes; and biobanking. Produced national recommendations for each, a number of which played a transformative role in driving change in policy and practice e.g., the development of a national genetics and genomics strategy.
3. **Growing the community:** Increased our member organisations from 39 to 47 and offered many types of support. We hosted 19 guest speakers at HRCI Board and member meetings, bringing new insights to both our community and to the speakers.
4. **Enabling shared learning:** Facilitated a PPI Shared Learning Group, which grew from 17 to 33 member charities. Maintained a reciprocal relationship with a parallel group of over 40 UK charities, leading to cross-border sharing of knowledge and resources.
5. **Developing valuable resources:** Published guides on the topics of charities & researchers partnering; patient registries; research governance for charities; and a PPI Toolkit.
6. **Advocating for improvements:** Produced 3 annual HRCI Position Papers, leading to an invitation by the Oireachtas Committee on Health to present on the importance of electronic health records in research.
7. **Promoting PPI:** Became a national partner in the PPI Ignite National Network, and the sole non-university entity to co-lead one of five work-packages. Contributed to the production of resources, represented national partners at funder meetings and provided an avenue for our members to engage in network activities.
8. **Changing research culture:** Awarded Wellcome Trust funding through a University College Cork-led grant, to create an engaged and inclusive university research culture.

9. **Supporting rare diseases:** Partnered with the Rare Disease Clinical Trial Network to co-host a PPI Liaison. This has led to a growing network of people affected by rare diseases being involved in the Network's activities.
10. **Emphasising research impact:** Launched a HRCI Research Impact Award and celebrated its inaugural recipient in 2022.
11. **Providing strategic advice:** Provided insights for national strategies and plans, including the HSE Action Plan for Research, the National Strategy for Genetics and Genomics, and the Children's Health Ireland Strategy for Research.
12. **Progressing genetics and genomics:** Participated in various national genetics and genomics initiatives and were invited to co-chair a HSE genetics and genomics working group.
13. **Supporting patient registries:** Hosted a national event in conjunction with the Cystic Fibrosis Registry of Ireland and partnered to produce a comprehensive guide to patient registries.
14. **Educating others:** Part of a small team to deliver two rounds of a Campus Engage course on 'Engaged Research & Innovation for Societal Impact: Building Capacity Across Ireland', which trained 60 participants.
15. **Providing pandemic support:** Assisted members throughout the COVID-19 pandemic and produced a report on its impact on them. Also conducted a survey of 8 Irish universities to better understand the impact of COVID on health research.
16. **Seeking evidence for our impact:** Partnered with Maynooth University and the HRB, to undertake research on the HRCI-HRB Joint Funding Scheme, providing independent evidence for how the Scheme is experienced and valued by all stakeholders.
17. **Enhancing communication:** Strengthened our communication efforts through website development, expanded social media presence, and diverse media. Increased our stakeholder mailing list from 500 to 1,400.
18. **Extending our influence:** Increased our visibility among key stakeholders and established numerous new collaborative partnerships, including acting as a partner on six successful research grants and as a member of 34 external committees and working groups.
19. **Featuring in the media:** Featured in more than 10 national media articles, radio interviews and podcasts.
20. **Strengthening our governance:** Maintained compliance with the Charity Governance Code and implemented stronger governance practices, covering reporting, financial management, HR, and overall organisational operations.

# REFLECTING ON OUR 2020-23 STRATEGY



# Developing the strategy

This strategy is the culmination of thorough assessment and planning. The preparatory steps involved:

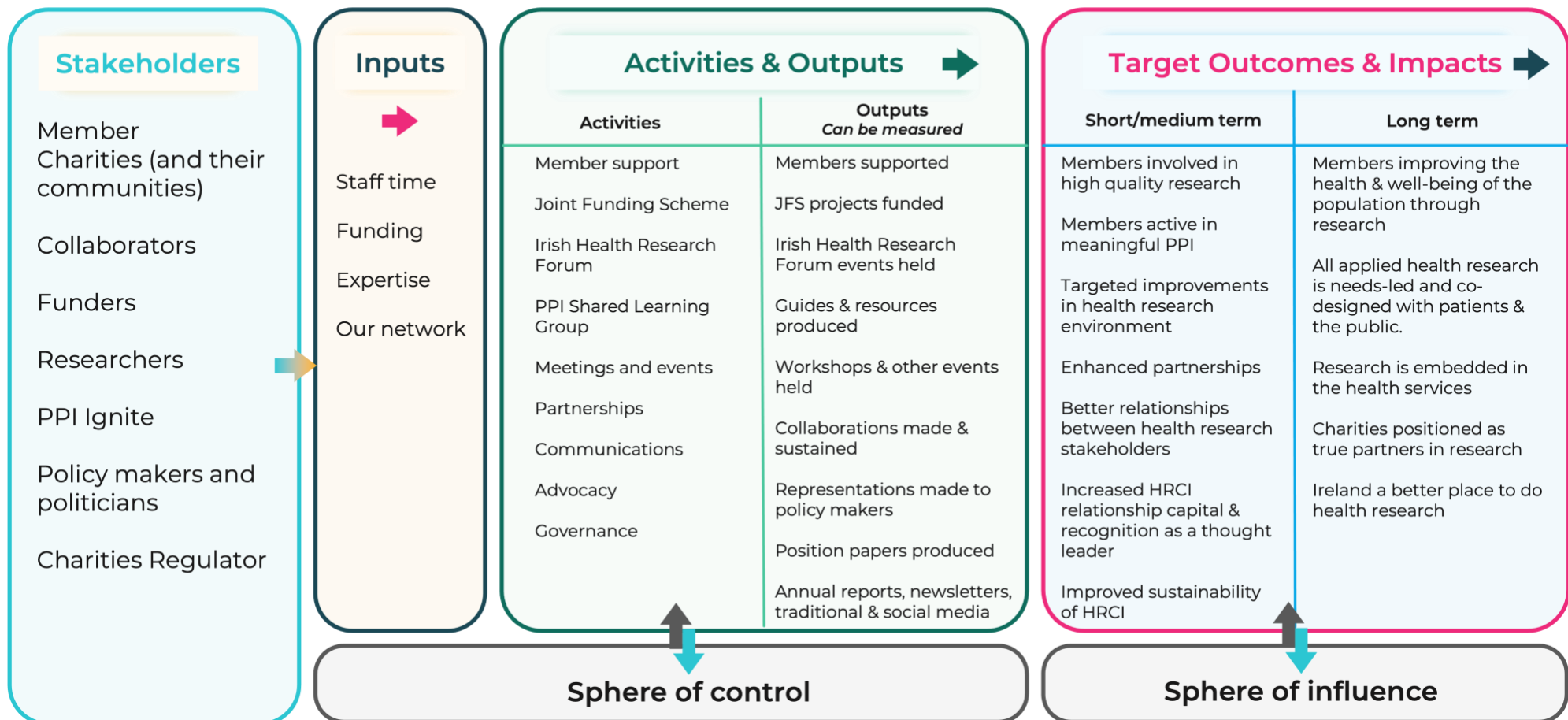
- Conducting a survey of HRCI members in late 2022 and into early 2023, gathering insights into their priorities and requirements (*with a 60% response rate*).
- Reviewing our progress against the objectives set in our prior strategy. Much of our prior strategy remains relevant and valuable.
- Being guided by our on-going scanning of the health research environment, including national policies, strategies, the outputs of our own Irish Health Research Forum and ongoing engagement with all stakeholders.
- Considering our resources, strengths, opportunities, weaknesses, and potential risks.
- Planning for the key performance indicators (KPIs) which we will use to measure our impact.
- Constructing a logic model to delineate the path toward achieving our desired impact (see below).
- Engaging in extensive consultation with and seeking guidance from the HRCI Board.

What  
do you  
value  
about  
HRCI?



**Image:** Responses to a December 2022 HRCI member survey question, asking what the respondents value most about HRCI. These and the other survey responses have guided this strategy.

# HRCI Logic Model (theory of change) 2023



## HRCI Strategy 2024 – 2027

We made very strong progress with limited resources over the course of our previous strategy. In line with our vision, it is now our intention to build that progress and to extend our influence further. In doing this, we will be responsive, collaborative and ambitious in our work. Below we outline our vision, values, four strategic aims and underpinning priorities.

### Our Vision

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities engaged in health, medical and social care research, collectively representing over 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.

*Note: We define 'health research' to mean research focused on advancing knowledge about human health, wellbeing, illness, care, service provision and population health. We are directly responding to UN Sustainable Development Goal 3: Good health and well-being.*

### Our Values

- We are ambitious and strive to continuously improve and innovate, to accomplish our vision of improving lives through impactful research.
- We are creative, resourceful and unafraid to challenge conventions when we believe there is a better way.
- We are open and transparent, acting with integrity in all our dealings.
- We are always guided in our actions by the needs of our member organisations and the people they serve.
- We value our colleagues and partners, treating each other with fairness, kindness and respect.
- We are collaborative in our approach and prioritise equity, inclusion, and dignity in all our relationships.

# Our Strategic aims

## 1. Empower HRCI 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 will be to foster 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. We will achieve this aim through the following objectives:

### a) Enhance capacity through meetings and events

We will respond to our members' needs and keep them abreast of key topics through meetings and events. These include our Board meetings to which we welcome members and invite speakers; information meetings; workshops; Irish Health Research Forum events; and events held in collaboration with others. In meeting this aim we will be responsive to member needs and the evolving health research landscape, extending to themes of research impact, PPI, charity involvement in research, research funding, rare diseases, and national policy and legislation.

### b) Develop and share resources

We will respond to members' collective and individual needs in health research through the provision of resources. Relationships with groups such as the PPI Ignite Network, the Charities Research Involvement Group (UK), the Association of Medical Research Charities (UK), the Ensuring Value in Research Funders Forum (International) and many others will support this objective. We will build upon existing resources and create new materials when necessary.

### c) Provide personalised and peer support

In a membership organisation of our size, it is possible to provide personalised support as our members require. Through new member inductions, one-to-one supports, information exchanges and dedicated networking time at HRCI meetings, we will create opportunities for our members to connect, exchange insights and learn from each other.

## **2. Facilitate excellent research through the HRCI-HRB Joint Funding Scheme**

The Joint Funding Scheme (JFS), run in partnership with the HRB, offers HRCI member charities the opportunity to secure matched funds for research projects. It is instrumental in supporting research of importance to their communities and ensures adherence to international best practices in research governance. Through working closely with the HRB and supporting our members through the process, we will strive to ensure the funding of excellent research. We will achieve this aim through the following objectives:

### **a) Partner with the HRB to manage and optimise the JFS**

We will partner with the HRB to effectively manage the JFS and to ensure that the scheme is meeting the needs of all stakeholders involved. This will involve reviewing each funding round, agreeing plans and documentation for the next, and co-delivering supports for charities and PPI reviewers. We will act as the first point of contact for charities and researchers, involving the HRB as required.

### **b) Support the submission of high-quality applications**

Through supporting our members in their research governance; guiding them through all the stages of the Scheme; promoting the Scheme with the research community; and encouraging strong PPI throughout, we will help to ensure the submission of high-quality funding applications to the Scheme.

### **c) Shift the focus towards impact for patients, service users and the wider public**

Through running a HRCI Research Impact Award for projects funded through the JFS, we will highlight the desire of our community for research to have impact beyond academic metrics. Through promoting the award and telling the impact stories that emerge we will contribute to wider conversations around research impact.

### **d) Acknowledging JFS successes and fostering interest**

At the conclusion of each funding round, we will organise an event to announce and celebrate the successful projects. It will also provide an important opportunity to acknowledge the many contributions made to a unique funding scheme. By fostering interest through these events and highlighting the importance of the JFS, we aim to bring it to the attention of a wider stakeholder audience.

### 3. Strengthen 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. With a focus on ensuring meaningful involvement, we will 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 will also work to highlight the value and perspectives of our members with the health research community and to amplify our efforts through partnerships with other PPI focused groups. We will achieve this aim through the following objectives:

#### a) Host a PPI Shared Learning Group for HRCI members

We will continue to run and develop our valued PPI Shared Learning Group for our members, to offer both HRCI and peer support. We will organise invited speakers on topics for which external input is of value and will continue our reciprocal relationship with the Charities Research Involvement Group in the UK. We will respond to the PPI needs of our members through managing a resource hub to share tools and information.

#### b) Promote the importance of charities as research partners

We will promote the value that charities can bring to research, highlight this with the wider health research community and explore ways to manage and increase their inclusion. We will build on our recently published guide to charities and researchers partnering for societal benefit.

#### c) Contribute to the PPI Ignite Network as a National Partner

We will continue in our leadership role in the PPI Ignite Network through the Steering Group and through multiple relationships across Network Lead Sites and partners. In particular, we will contribute as a co-lead of a work package to build PPI capacity across communities.

#### d) Partner with other organisations to increase PPI and charity involvement

We will partner with other organisations with an interest in PPI to increase the quality and quantity of PPI undertaken in Irish health research. Of particular note, we will partner with the Rare Disease Clinical Trial Network to co-host a PPI Liaison and with UCC on a Wellcome Trust-funded initiative to strengthen engaged research.

*\*Please note that the term PPI 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.*

## 4. Positively influence Ireland's health research landscape

As a collective voice representing 45+ health research charities, we recognise our mandate and 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 on behalf of our members and their communities.

We anticipate a focus on a range of topics which include PPI; genomics; patient registries; research ethics; biobanks; rare disease research; research impact; legislation of relevance; and the progression of all forms of health research, including health services and population health research. We will achieve this aim through the following objectives:

### a) Run the Irish Health Research Forum

We will continue to convene the ever-stronger Irish Health Research Forum. This will involve supporting a high-level, multi-stakeholder Steering Group; running twice-annual events on pertinent topics; and producing reports and recommendations which will be shared with all key stakeholders. We will increase our focus on translating these recommendations into impact.

### b) Maintain and increase our strategic partnerships

We will continue to invest in strategic partnerships that align with our strategy and to explore areas of interest relevant to our member organisations. Among these will be a number of initiatives in genetics and genomics, the European Rare Disease Research Alliance and the Ensuring Value in Research Funders Forum.

### c) Produce an annual HRCI Position Paper

We will aim to articulate our members' views and call for action on key health research topics through an annual position paper. We will disseminate this paper to relevant politicians, policy makers and wider stakeholders.

### d) Advocate for our members' interests

Through our steadily increasing profile, we receive many invitations to attend meetings, sit on committees and present at events. We also proactively seek engagements with strategic potential. We will use these opportunities thoughtfully and wisely to increase the profile of our members and to further our collective interests.

# Underpinning activities

There are a number of underpinning activities that are essential for the successful implementation of all aspects of this strategy and are outlined here.

## 1. Excellent governance

In order to operate in the most effective and transparent way possible, and to set a positive example for our members, it is imperative that we continue our excellent governance. We commit to:

- Maintaining a strong Board of Directors, which will meet six times per year, comprising of Directors drawn from both member organisations and external organisations and with a diverse range of valuable skills. Three Board sub-committees will support their work – the Staff & Finance Committee (to meet six times per year), the Advocacy and Communications Committee (to meet three times per year) and the Appointments Committee (to meet as required).
- Being guided in our management of the Irish Health Research Forum by an excellent Steering Group of 18-20 diverse stakeholders.
- Undertaking an annual review of our compliance with the Charity Governance code to ensure continued adherence to standards far exceeding those expected of a charity of our size.
- Undergoing an independent financial audit on an annual basis and ensuring that our statutory financial statements align with Statement of Recommended Practice (SORP) standards and are publicly available on our website.
- Producing in-depth, engaging annual reports, which review our achievements against our strategic goals. We will increase our emphasis on reporting both quantitative and qualitative impact.
- Ensuring compliance with all relevant legislation including the Charities Act 2009, the Companies Act 2014, the Lobbying Act 2015, GDPR, employment legislation and equality legislation.
- Maintaining a suite of policies and controls to guide our operations, categorised into financial and risk policies; HR policies; terms of reference; codes of practice/conduct; membership policies; and others pertaining to data protection and complaints/feedback.
- Providing detailed reports to our funders, including Pobal and the HRB, with a focus on reporting our impact rather than mere outputs.
- Being guided by our charitable objectives, vision statement, values and this strategy, as we develop detailed annual action plans and in all of our activities.

## 2. Strong communications

All of our strategic aims and objectives can be strengthened through strong communications. In this regard, we will:

- Maintain an engaging, clearly structured website, serving as a valuable resource for members and all stakeholders.
- Continue our strong engagement on social media, utilising trusted and appropriate channels.
- Produce three newsletters a year, informing our members, collaborators and wider stakeholders about our activities and relevant news.
- Maintain a member mailing list for important information and ad hoc news mailings known as 'HRCI snippets'.
- Maintain and expand a diverse mailing list of people interested in health research to alert them to events, publications and other important news.

## 3. Increased sustainability

We recognise that none of our activities are possible without a sustainable organisation. Over the period of this strategy we will aim to renew and increase our core income streams and reduce our dependence on any single funding source. We will consistently investigate ways to increase our sustainability, through:

- Partnering on research grant applications.
- Investigating ways to recover some of the costs for activities of value to other stakeholders.
- Sharing activity costs through partnerships.
- Maintaining our membership numbers and slowly increasing our membership.
- Increasing our income through industry sponsorship.

## **For further information**

For further information on our activities, governance, finances or organisational structures, please visit our website. Our most recent annual report is generally a great place to start! See here: <https://hrci.ie/annual-reports/>

We welcome any views you have on our strategy. Please don't hesitate to get in touch.