

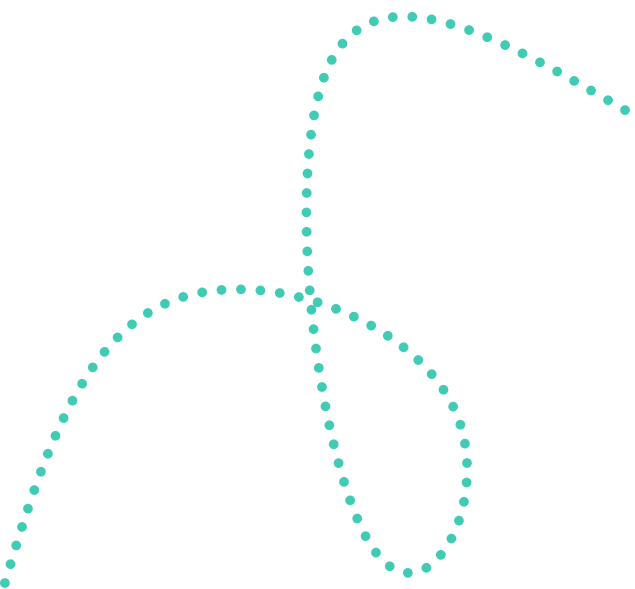
# Managing and responding to shifting paradigms in the health research landscape

Learnings from the Health Research Charities Ireland & Health Research Board Joint Funding Scheme

## SUMMARY REPORT

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We would particularly like to thank all those who kindly agreed to share their experiences at interview – we appreciate your time and insights.

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## About the Authors

This project was conducted by **Dr. Nicola Mountford**, Principal Investigator, Associate Professor and PhD Director at the School of Business at Maynooth University and **Emily Merrick**, Research Assistant at the School of Business at Maynooth University.

Interviews and document reviews were conducted by the research assistant under the supervision of Dr. Mountford. HRCI and HRB acted as subject matter experts and facilitated access to interviewees and relevant documentation.

Dr Mountford's research examines institutional dynamics in healthcare. She co-founded the ENJECT European research network on connected health, and lead-authored an ENJECT technical report examining the Connected Health context in 19 European countries. At different times, she has been a member of UCD's Healthy Ireland Research and Evidence Group and Ireland's eHealth Ecosystem Working Group. In 2016 she was awarded a Fulbright Scholar's Award to study the eHealth market in New York. She is currently a member of the PPI Ignite network and is a firm believer in a strong PPI voice in healthcare research and policy decision-making.

# 1. Introduction

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## Foreword

Over the Summer of 2022, I worked with Dr Sarah Delaney and Dr Avril Kennan of Health Research Charities Ireland (HRCI) alongside Dr Aoife Cahill and Dr Anne Cody of the Health Research Board (HRB). Our goal was to develop a collaborative research project that would focus on the joint funding scheme run by HRB, HRCI and HRCI member charities. We were interested in how decisions were made and influenced within this scheme and particularly in the role of the patient voice through the Public and Patient Involvement (PPI) aspects of the scheme.

I applied for funding to Strand 1a of the Irish Research Council's New Foundations scheme: Enhancing Civic Society. This strand supports "small, discrete collaborative projects between researchers and civic society groups in the community and voluntary sector". I was delighted when the project was awarded funding and commenced work on the project just before Christmas 2022. Project activities were spread over nine months. The first three months were focused on scoping the scheme process. Data collection and analysis took place between months three and seven while the final two months concentrated on dissemination.

The goal of this project was to both influence health related funding decisions and inform funding scheme design so that projects are commissioned, designed and funded to enhance PPI in Ireland and beyond. This maps directly onto Sustainable Development Goal (SDG) 3: Ensure healthy lives and promote well-being for all at all ages. The objectives articulated in SDG3 require excellent and innovative research as well as strong patient and healthcare practitioner uptake of resulting solutions. I believe that strengthening funding decision making processes for health research and incorporating impactful patient involvement in such decisions is key to both innovation and adoption. I hope this project will encourage partnerships for change between patients, the wider public, and healthcare researchers. This will, in turn, stimulate improvements to health and wellbeing across a wider range of stakeholders and generate new knowledge which is effectively exchanged to improve policy, practice and services.

A detailed report of findings has been prepared for the collaborative research partners. This summary report aims to provide a high-level overview of the project, drawing out the key high-level findings for a broader audience.



**Dr Nicola Mountford**  
**Associate Professor**  
**Maynooth University**

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### Health Research Charities Ireland

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. They champion their members' interests, to enhance the environment for health research in Ireland. They empower their members to realise their shared vision of improving lives through impactful research.

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### Health Research Board

The Health Research Board (HRB) is a State Agency under the Department of Health which supports and funds health and social care research, providing evidence to inform policy and practice. The HRB's mission is to support research that improves people's health, promotes evidence-informed care and creates solutions to societal challenges.

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### Joint Funding Scheme

The Joint Funding Scheme (JFS) offers HRCI member charities the opportunity to secure matched funds from the HRB to support research of importance to their communities. The charities work with researchers to develop and select project proposals which are reviewed by an expert multi-disciplinary panel convened by the HRB, towards making a funding decision. To date, 153 awards have been made, representing a total investment of over €25 million. Figure 1 gives a high-level overview of the key steps in the HRB/HRCI Joint Funding Scheme.

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### Public & Patient Involvement

Public and Patient Involvement (PPI) in health research refers to a process whereby members of the public and/or patients are involved in planning and doing research from start to finish including public dissemination of the research results. Nationally, and internationally, PPI is fast becoming an essential part of health research. However, PPI often happens too late in the research process and can become a 'tick-box' exercise. In addition, it can be difficult to change long-established roles such as that of the academic expert. PPI places high value on effectiveness, relevance, validity, representativeness and the development of an evidence base. Therefore, PPI can assist in meeting funder obligations to make the best use of taxpayer or philanthropic money. Both the HRB and HRCI are strongly committed to driving and supporting PPI in health research.

# About the Funding Scheme

Figure 1: Joint Funding Scheme Overview



## HRB OPENS SCHEME

- MEETING OF HRB AND HRCI TO REVIEW SCHEME, AGREE NEW ROUND, AND UPDATE ANY PROCESSES/DOCUMENTATION.
- THIS IS BASED ON PREVIOUS YEARS' STAKEHOLDER-FEEDBACK.

## CHARITY OPENS CALL, REVIEWS & SELECTS PROPOSALS

- HRCI IS FIRST POINT OF CONTACT FOR CHARITIES
- CHARITIES OPEN CALLS FOR EXPRESSIONS OF INTEREST &/OR FULL APPLICATIONS
- RESEARCHERS SUBMIT PROPOSALS TO CHARITIES
- CHARITIES REVIEW & SELECT PROPOSALS TO BE SUBMITTED TO HRB - THIS INCLUDES INTERNATIONAL PEER REVIEW & APPLICANT RESPONSE



## SUBMISSION OF APPLICATION TO HRB

- CHARITY SUBMITS ABSTRACT
- RESEARCHER SUBMITS FULL PROPOSAL TO CHARITY
- CHARITY ENDORSES PROPOSAL AND SUBMITS TO HRB



## JOINT SELECTION PANEL

- HRB CONVENE AND ORGANISES SELECTION PANEL/PROCESS ON BEHALF OF THE HRCI & CHARITY PARTNERS
- PANEL RECOMMENDS PROPOSALS TO BE FUNDED



## HRB APPROVE RECOMMENDED PROJECTS

- HRB MANAGES THE RESEARCH FUND AND REPORTING PROCESS DIRECTLY WITH THE RESEARCHERS AND THEIR INSTITUTIONS





# 2. Methodology

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Scheme Documents Reviewed

## Two Phase Approach

A two-phase approach was used to gather data for this study:

- **Phase 1:** Document review to scope the scheme processes. The aim was to understand the mechanics of the scheme and to develop an end-to-end map of the scheme process, including key decision points. In total 29 documents were reviewed as part of this process.
- **Phase 2:** an inductive, qualitative methodology was used to capture the experiences of the key stakeholders of the scheme. In total 27 people were interviewed for this study.

Ethical approval was received from Maynooth University Research Ethics Committee.

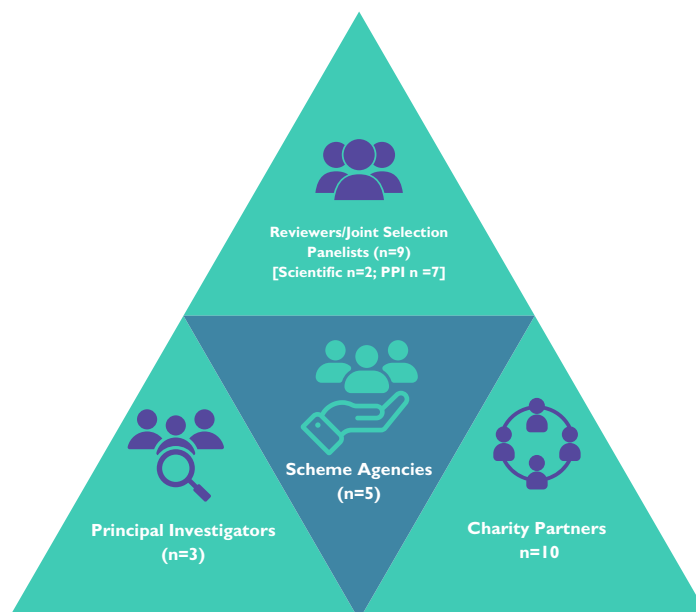
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1-2-1 Qualitative Interviews

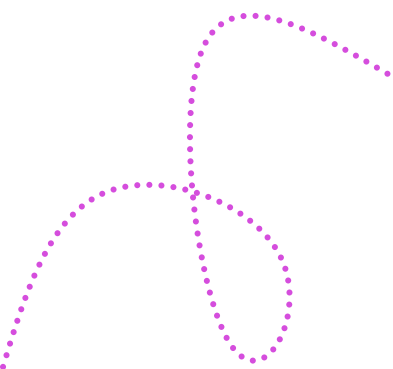
## Interview Sample

Four key stakeholder groups were identified and purposively sampled for:

1. Scheme agencies including project advisory board members (n = 5)
2. Charity partners (n = 10)
3. Reviewers/Joint Selection Panelists:
  - Scientific reviewers / joint selection panelists (n = 2)
  - Public & Patient Involvement (PPI) reviewers/joint selection panelists (n = 7)
4. Principal Investigators (PI) (n = 3).







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## Limitations

As with all research projects, there are limitations to this study – the main ones we see in this case being:

- All data was collected retrospectively between one and two years following the involvement of the stakeholders in the process. Therefore, the potential role of recall bias should be recognised.
- International peer reviewers who did not take part in panel discussions were not interviewed as part of this project. Furthermore, the perspectives of those who did not engage in the last round of the scheme or who have never engaged are not represented in this study.
- Potential participants received project introductions and interview invitations from well-respected scheme agencies, one a state agency and major research funder.
- We recognise the role we as researchers played in the research and are aware our own biases, knowledge, views and opinions could have impacted the research process. Thus, we have reflected on those throughout the project.

# 3. Key Findings

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## An Important and Valuable Scheme within the Health Research Funding Landscape

- Overall across the board the key stakeholders who participated in this study believe that this is a rewarding and mutually beneficial funding scheme which they feel adds real value in the sector. Participants suggest that it provides a model for citizen-involvement in public research decision-making processes that could be used across research sectors.
- All parties value the scheme and wish to see it continue. As with any funding scheme there is a learning curve from initial launch, and the scheme has already been changed year on year via a process of continuous improvement based on key stakeholder input and feedback.

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## Paradigm Shift

### Breaking new ground

- The beauty of the scheme is that it brings together a variety of diverse stakeholders to create an innovative model of how healthcare research is done. It creates new opportunities in terms of what kinds of research get funded, who gets to have their research funded, and whose voices are heard when decisions are being made. It is in many ways a paradigm shift for all parties involved in the process, and with that comes a learning curve.
- There are three parties involved in the funding/administration side of the scheme (the HRB; HRCI; and the Charity Partner), there are PPI representative members at both the charity partner level and the HRB selection panel level, and there are the researchers who have submitted the research proposal. All of these stakeholders are operating together in an evolving space characterised by unsettled questions and a diversity of perspectives.
- Throughout the interview analysis and subsequent findings, we find stakeholders breaking new ground within their own personal remits, and often within their own personal perceived areas of expertise. Whether that is a researcher fundamentally engaging with PPI in a whole new way than they have previously; a PPI representative reading themselves into complex research and research evaluation processes; or a charity partner managing a rigorous process of research proposal review and international peer evaluation.



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## Managing the Scheme

The scheme requires stakeholders to operate outside of their traditional remits. Within this context a series of key factors are highlighted that can enable or hinder the successful implementation of such a scheme, and which are particularly important in ensuring that power and decision-making can be democratised in a way that honours the mission of the scheme:

### Scheme Administration

Charity partners, PPI representatives and researchers comment that the complexity of the application forms and the double peer-review process is a significant burden on all parties involved. Securing international peer reviewers emerges as a particular pain point for charities.

### Communication

- The diverse set of stakeholders involved in the scheme forces all parties to be clear and explicit in their language, definitions and communication. Taken-for-granted ways of knowing, terminology, processes etc. need to be examined and presented transparently.
- Lay summaries push researchers outside of existing expectations of academic language – and writing in this way is often a new skill to be learned. PPI can mean different things to different people, so each party needs to be explicit in their definitions at every stage of the process.

### Training

Participating in the scheme presents a steep learning curve particularly for the charity partners, PPI representatives and researchers. All parties are asked to operate outside of their traditional remits. In order to do this effectively, participants in this study believe that training is an important enabling factor - particularly for researchers and PPI representatives:

#### Researchers:

- Must learn how to communicate their research in a way which can be understood by a lay reader, and how to clearly explain the PPI elements of their projects in the proposal phase.
- Must understand how to ‘do PPI’ properly, from project inception to dissemination – which can be a steep learning curve.

#### PPI representatives:

- Must understand how to review proposals and what is involved in being part of a research project review panel, particularly in terms of their roles and responsibilities.
- Participants in this study see training as key to the PPI voice being heard and valued. Charities are seen as having a role here as ‘bridge’ between the two worlds.

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# Striving for Balance

## Power & Decision-Making

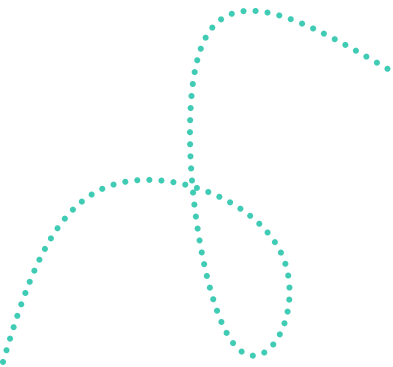
The power relationship between the HRB and the charity partners within the scheme process is perceived to be at times straightforward, and at times complex. The image that emerges from the data is of a group of stakeholders working together to find their feet, their confidence and their voices, in an evolving space.

Charities choose the area they want researchers to focus on, and choose which proposals to submit to HRB. The HRB then manages the panel review and overall funding process. Ultimately the HRB say that the funding decision lies with the selection panel, which includes PPI representatives. Those PPI representatives, however, carry less weight in terms of their voice in the final decision-making process than scientific members of the panel. Regardless of this, PPI representatives generally report feeling valued and heard in the process, and believe that their voice carries weight and power in the decision-making process.

## Balance

Balance is a concept which comes up across the project:

- How do we balance perceived ‘scientific rigour’ with inclusion of the charity partner and PPI voice which is seen as providing knowledge which is grounded more in lived-experience?
- Charities are both funders and participants within the scheme who see the HRB as a champion for their voice in this scheme. Ultimately the relationships are not necessarily perceived as being ‘equal’ in terms of decision-making power, but rather as symbiotic and mutually beneficial. The HRB and HRCI help charity partners achieve what they could not do alone.
- PPI representative participation across the scheme comes across as complex and complicated in terms of what constitutes ‘lay’ versus ‘professional’ PPI representation. Praise for the ‘professionalism’ with which PPI reviewers approached their task was at times accompanied by a concern as to how representative they were of the lay public. Complexity also emerges in terms of the role of condition/disease specific experts versus PPI generalists. While the overall sentiment is positive, achieving a balance between embedded, meaningful PPI (which may require training and expertise) and tokenistic, powerless PPI (which may appear more generally representative) remains challenging.



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## Confidence and Reward

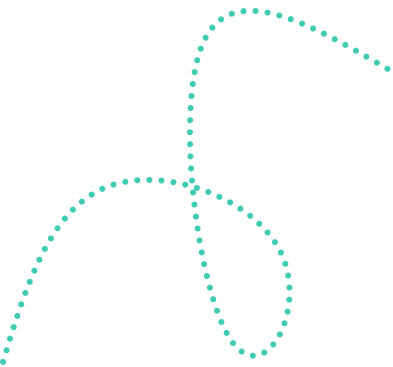
- As outlined herein, the scheme requires all parties involved to operate outside of their traditional roles, which can be challenging. Stakeholders do, however, report that the reward is equal to the challenge.
- It is complex and complicated to do things differently, to learn new skills, to let go of power (in the case of researchers, scientific panel members and charity partners); and to step comfortably and confidently into spaces known for their (often exclusionary) complexity of language and closed-ness to knowledge based on the lived-experience (in the case of PPI representatives). Charity partners are tasked with performing elements of the role traditionally associated with well-resourced, single-purpose research funding organisations.
- In all cases however, the effort required to learn these new skills, is rewarded with increased skills, significant confidence-building, and ultimately a feeling of deep reward and accomplishment. People talk of the process being inspirational, enthusing, impactful, and ultimately community-building.

## Benefits, Challenges & Enablers by Charity-type

Three types of charities were referenced by participants within the study: small charities, larger charities and rare-disease charities. Participants identified a range of specific characteristics that affected the challenges, enablers, and benefits experienced by each charity-type in relation to the funding scheme. These are summarised in the following table (Figure 2):

**Figure 2: Benefits, Challenges & Enablers by Charity-type**

	Large Charities	Small Charities	Rare-disease Charities
Benefits	<ul style="list-style-type: none"> <li>• Opportunity to maximise resources; and have HRB manage the call and fund on their behalf</li> </ul>	<ul style="list-style-type: none"> <li>• Only way that many could fund a large/ significant piece of research</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity to fund research in a wider context where it can be difficult for rare diseases to get funded</li> </ul>
Challenges	<ul style="list-style-type: none"> <li>• Managing researcher relationships and networks –</li> <li>• May have a large network of research stakeholders to manage</li> </ul>	<ul style="list-style-type: none"> <li>• Steep learning curve required to engage with the process - international peer review etc.</li> <li>• Lack of research staff/resources.</li> </ul>	<ul style="list-style-type: none"> <li>• Often small national research community to draw from.</li> <li>• Lack of research staff/ resources</li> </ul>
Enablers	<ul style="list-style-type: none"> <li>• Dedicated research resources</li> <li>• Experience and expertise of working with large network of researchers</li> </ul>	<ul style="list-style-type: none"> <li>• Existing researcher relationships</li> <li>• Provision of additional support from HRCI</li> </ul>	<ul style="list-style-type: none"> <li>• Existing researcher relationships</li> <li>• Provision of additional support from HRCI</li> </ul>



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## Conclusion

This project looked at one funding scheme in one country and sought multiple perspectives on how the PPI voice was heard in key decision-making processes. While it does not claim generalisability beyond this scheme, there are certainly lessons to be learned. Different types of charities do experience the scheme differently, with smaller charities needing more support to fully reap the benefits offered. The Joint Funding Scheme is, however, roundly praised by all stakeholders. We suggest that this stems from its genuine value base that emphasises open-mindedness, transparency, equality and respect.

Participants within the scheme find themselves safely stepping outside their comfort zone and experiencing a sense of personal growth as a result. We hope that this report will be helpful to other funding schemes and decision-makers seeking to redesign their processes towards more inclusive decision-making.



