Health Research Charities Ireland

Members' guide

Health Research Charities Ireland (HRCI)

Who we are

- National umbrella organisation of 45+ charities engaged in health, medical and social care research
- Collectively representing over 2 million people in Ireland
- Championing members' interests to enhance the environment for health research in Ireland
- Empowering members to realise a shared vision of improving lives through impactful research

What we do

- Enhance health research through Patient and Public Involvement (PPI), hosting a PPI Shared Learning Group for our members
- Partner with the HRB to manage the HRCI-HRB Joint Funding Scheme, and raise awareness of the scheme
- Inform and support members to increase their capacity to engage in health research
- Manage the Irish Health Research Forum and run 2 meetings a year

Our member organisations

HRCI has 46 member charities and they range from large research funding charities to small, voluntary-run patient organisations.

The members of HRCI invested almost €13 million in research in 2023 and every extended family in Ireland is connected to at least one of these organisations. 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.

***Note**: while we sometimes use the terms 'patients', due to our strong focus on health research, some of our members represent older adults, carers and other groups in society*.

Our 2024 – 2027 strategic aims

1. Empower HRCI members in their research activities

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

3. Strengthen PPI and the involvement of our members in health research

4. Positively influence Ireland's health research landscape

Holding inclusive Board & Member Meetings

- Welcoming all members to 5 of 6 meetings per year
- Providing added value through expert speakers & research information exchange between members
- Encouraging conversations over lunch

Offering events & networking opportunities

- Hosting talks to inform members on key topics
- Offering workshops & seminars on relevant topics
- Hosting the PPI Shared Learning Group
- Running two Irish Health Research Forum events per year

Developing guides & toolkits

- Charities & researchers partnering for societal benefit
- Unlocking the potential of patient registries: a guide for success
- Making a Start: a toolkit for research charities to begin a PPI relationship
- A governance guide for health research charities

How do we support you in your research activities?

What is the JFS?

- A **unique scheme** that brings together the HRB and HRCI to co-fund projects of key relevance to charities
- Projects are funded **50/50 by the HRB and the member charity** (very small charities receive 75% HRB funding)
- Runs **every 2 years**, the HRB makes a **€2 million** contribution to each round
- To date **163 awards** made, total investment of over **€28 million**
- Supports research projects of **12-36 months duration** up to a max of **€300,000**

What is funded by the JFS?

Everything bar RCTs including

- Basic biomedical research
- Applied biomedical research
- Clinical research (not RCTs)
- Population health research
- Health services research
- Psychological and social research on health

HRCI member charities open calls (EOI/full)

EOIs shortlisted to invite full applications

→

Charities identify inter-national peer reviewers (managed through HRB grants management system)

→

Charities review and shortlist applications

→

Joint Selection Panel meet and recommend projects for funding

→

HRB Board approves successful projects

→

Contracts are issued and projects started

How does the Joint Funding Scheme work?

Check out the **FAQ** that we keep updated based on real queries

Take a look at what was funded in **past rounds**

Things to help

- Avail of our mentorship programme
- Take a look at our guide to research governance
- Listen and learn until you are ready to participate

How can I prepare for the Joint Funding Scheme?

Running a PPI Shared Learning Group

- Holding four meetings per year
- Hosting guest speakers
- Maintaining a shared resources folder
- Managing a reciprocal relationship with a UK group of charities

Offering PPI supports in response to needs

- Hosting workshops & events
- Developing guides & toolkits
- Offering individual PPI support
- Supporting PPI in the Joint Funding Scheme

Being a central partner in the National PPI Ignite Network

- Keeping member perspectives at the heart of PPI nationally
- Offering opportunities to engage with the network

How do we support patient & public involvement (PPI)?

IRISH HEALTH RESEARCH forum

Running the Irish Health Research Forum

- Bringing together all health research stakeholders
- Managing a diverse, high-level Steering Group
- Holding two events per year
- Addressing big topics such as genomics, research in the health service, the use of health data, research impact etc.

Actively advocating on behalf of members

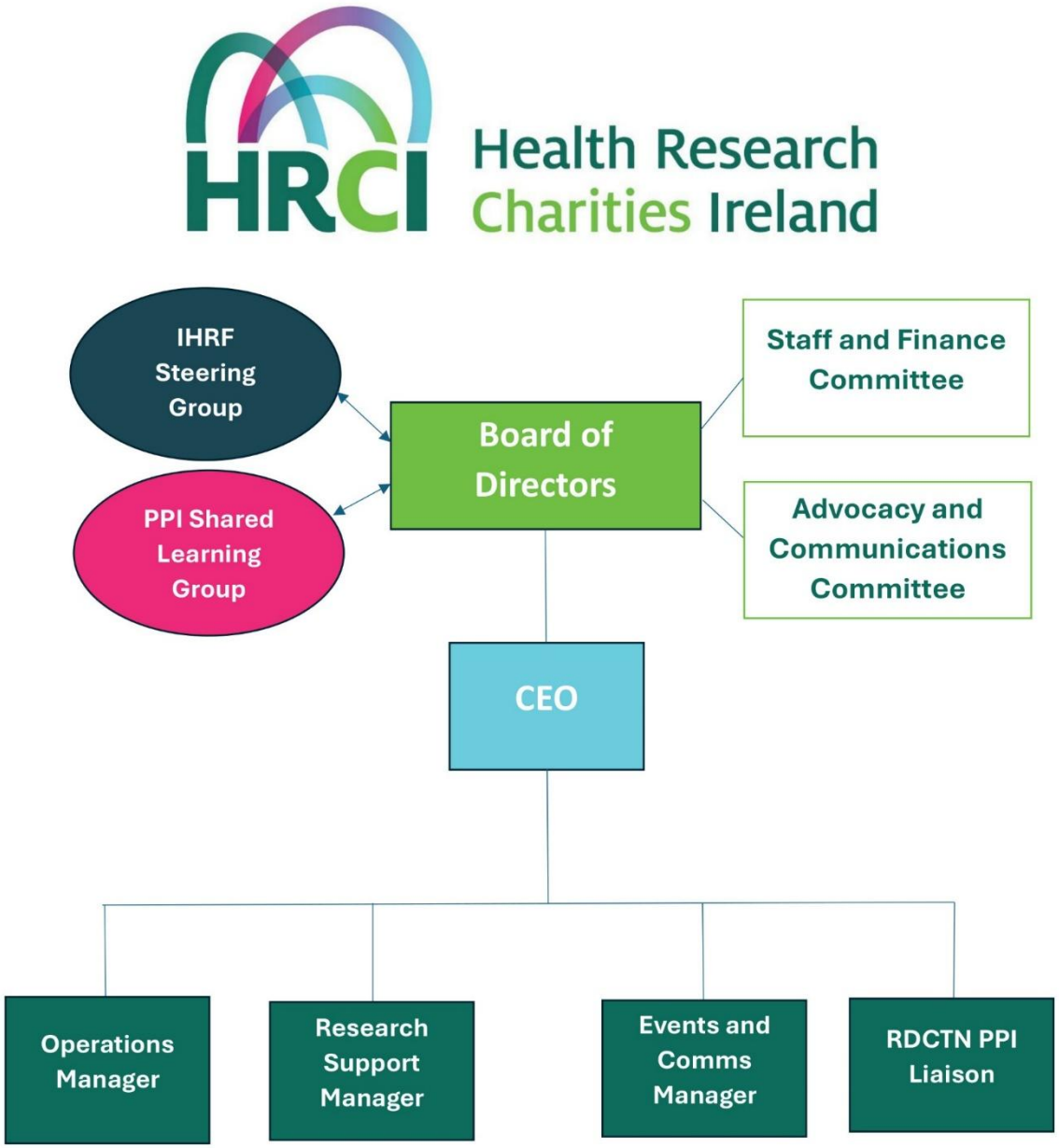
- Producing Annual position papers
- Making submissions to consultations
- Disseminating reports on member surveys
- Meeting politicians & policy makers

Supporting rare disease research

- Ensuring the Joint Funding Scheme works for rare disease charities
- Partnering on the Rare Disease Forum & leading on one meeting per year, focused on research
- Attending meetings with Department of Health, ministers and politicians
- Contributing to publications such as the Easyguide to Rare Diseases

How does HRCI strengthen health research nationally?

HRCI Organisational Structures



HRCI staff

Dr Avril Kennan: CEO

Marie Downes: Operations Manager

Linda McGrath: Events and Communications Co-ordinator

Dr Sarah Delaney: Research Support Co-ordinator

Dr Cassandra Dinius: Patient and Public Involvement Liaison, Rare Disease Clinical Trial Network

HRCI Board

Brian Lynch, HRCI Chair & Operations Manager and Deputy Head of School - Partnerships, School of Population Health, RCSI

Dr Sinéad Hickey, HRCI Secretary & Head of Advocacy, Research and Policy, DEBRA Ireland

Jonathan O'Connell, HRCI Treasurer & Chief Financial Officer, Phoenix Technologies

Dr Lesley O'Hara, CEO, St John of God Research Foundation

Dr Frances Drummond, Research Manager, Breakthrough Cancer Research

Dr Claire Kilty, Head of Research, Irish Cancer Society

Dr Laura Brady, Digital Health Innovation Lead, FutureNeuro Research Centre, RCSI

Dr Bernadette Rock, Head of Research and Regulatory Data Insights, Medical Council Ireland

Niamh Gavin, CEO, Adelaide Health Foundation

Mike Walsh, Central Remedial Clinic

Dr Sarah Tecklenborg, Interim CEO, Cystic Fibrosis Ireland

How can I get the best out of being a HRCI member?

Join us for meetings & events. We know it is not always possible but come along when you can. This is where you will meet other members, connect with them and learn from each other. At Irish Health Research Forum events you will also meet all types of people involved in health research in Ireland and will grow your organisation's network.

Come to Board & Member Meetings in particular. Our open Board meetings are a little unusual but also special. This is where you will hear from guest speakers, learn about HRCI's activities and hear what other members are up to.

Join the mentorship programme. Unless you already have lots of experience in health research, mentorship from one of our long-term members will be invaluable in developing your research activities.

Share your wins and your challenges. This is how members learn from and support each other and how HRCI gets to know about the things that are important to you.

Don't be shy. We sometimes put a call out for speakers, for other roles or seek your views. We are always very grateful to hear back from you and it really helps us to do our work.

Ask for help. Between the staff and the Board we have huge experience in all things relating to health research so always feel free to ask our advice.

Making sense of the discussions

We try and avoid jargon and acronyms at our meetings but inevitably some sneak in. Don't worry, none of us knew much about the world of health research in Ireland when we joined the HRCI community. It can take a bit of time to get to grips with it all but we've prepared this list of commonly used acronyms to help. And never be afraid to ask for an explanation of what is being talked about.

Acronym	Acronym in full	Explanation
AMRC	Association of Medical Research Charities	HRCI's equivalent in the UK
BME	Black & Minority Ethnic	Can also be written BAME. This term is sometimes used when we are discussing equality, diversity and inclusion
Campus Engage		This is a platform for promoting civic engagement activities in Irish higher education. It is based at the Irish Universities Association
CTI	Cancer Trials Ireland	A not-for-profit registered charity with a mission to develop and provide access to the most efficient and effective cancer clinical trials network. Their everyday functions include planning, opening, coordinating, supporting, monitoring and auditing cancer trials in Ireland
COI	Conflict of Interest	
CRA	Charities Regulatory Authority	
CRIG	Charities Research Involvement Group (UK)	This is the UK equivalent of our PPI Shared Learning Group and we have a reciprocal relationship with them

Acronyms (continued)

Acronym	Acronym in full	Explanation
DFHERIS	Department of Further and Higher Education, Research, Innovation and Science	
DoH	Department of Health	
DPC	Data Protection Commission	
DPOs	Data Protection Officers	
DPIA	Data Protection Impact Assessment	
ECRIN	European Clinical Research Infrastructure Network	
EDI	Equality, diversity and inclusion	
EHR	Electronic health record	
EI	Enterprise Ireland	
EMA	European Medicines Agency	
EPAG	European Patient Advocacy Group	
ERNs	European Reference Networks	These are virtual networks bringing together healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialised treatment and a concentration of knowledge and resources
EUPATI	European Patients' Academy on Therapeutic Innovation	
EURORDIS	The European Organisation for Rare Diseases	

Acronyms (continued)

Acronym	Acronym in full	Explanation
GEMS	(HRB's) Grants E-Management System	Used for submitting Joint Funding Scheme applications to the HRB
HEI	Higher Education Institution	
HIQA	Health Information and Quality Authority	
HPRA	Health Products Regulatory Authority	
HRB	Health Research Board	
HRCDC	Health Research Consent Declaration Committee	
HRR	Health Research Regulations	These are laws that govern the use of personal data for health research purposes. They outline mandatory suitable and specific measures that ensure that health research in Ireland is conducted using best practice principles of information governance in line with GDPR requirements
HTA	Health Technology Assessment	A multidisciplinary research process that collects and summarises information about a health technology. The term 'health technology' includes any intervention that may be used to promote health; to prevent, diagnose or treat a disease, or in rehabilitation or long term care
IP	Intellectual property	
IPHA	Irish Pharmaceutical Healthcare Association	
IPPOSI	Irish Platform for Patient Organisations, Science and Industry	

Acronyms (continued)

Acronym	Acronym in full	Explanation
IRC	Irish Research Council	
IRNM	Irish Research Nurses and Midwives	
IUA	Irish Universities Association	
JFS	HRCI-HRB Joint Funding Scheme	
JLA-PSP	James Lind Alliance Priority-Setting Partnership	Priority-Setting Partnerships are partnerships between clinicians, patients and carers who work together to identify and prioritise gaps in the evidence base in particular areas of health and care that could be answered by research. The James Lind Alliance is set up to facilitate these partnerships using a specific method
KEDS	Knowledge Exchange and Dissemination Scheme	A HRB scheme that offers the potential of additional funds for projects already funded by the HRB, for the purposes of knowledge exchange and dissemination
KTI	Knowledge Transfer Ireland	The national office that helps business to benefit from access to Irish expertise and technology by making it simple to connect and engage with the research base in Ireland
MRCG	Medical Research Charities Group	The former name for HRCI
NCTO	National Clinical Trials Office	Formerly called HRB – Clinical Research Coordination Ireland
NCPE	National Centre for Pharmacoeconomics	
NIHR	National Institute for Health Research (UK)	
NIRDP	Northern Ireland Rare Disease Partnership	

Acronyms (continued)

Acronym	Acronym in full	Explanation
NRDO	National Rare Disease Office	
NRECs	National Research Ethics Committees	These committees are responsible for reviewing research proposals in prescribed areas of health research, with the aim of providing single national ethics opinions that are respected nationally
ORPHAcodes		Each of the nearly 7,000 rare diseases listed on the Orphanet website has been designated an Orpha code, making this coding system more effective for rare diseases than other commonly used systems
Orphanet		The portal for information on rare diseases and orphan drugs (www.orpha.net)
PACE-R	Patient Advocate Centred Education Based Research	A UCD summer research programme for students in the School of Medicine
Patient Registry		Patient registries capture information systematically over long periods of time, at a population level (e.g. a particular disease) and with a view to answering current and future research questions
PI	Principal Investigator	
PPI	Patient and Public Involvement	In the HRCI context this is usually in relation to research but can also apply to healthcare
PPI Ignite National Network		Also sometimes called the National PPI Network. The network promotes excellence and inspires innovation in PPI in health and social care research in Ireland

Acronyms (continued)

Acronym	Acronym in full	Explanation
PPI SLG	Patient and Public Involvement Shared Learning Group	This is a group of HRCI member charities who meet 4 times a year with the aim of encouraging and supporting shared learning about PPI. The group works together to enable the development and sharing of PPI resources
PQs	Parliamentary Questions	Parliamentary Questions are tools that can be used by Oireachtas members to seek information or to press for action. They oblige Ministers to explain and defend the work, policy decisions and actions of their Departments
QoL	Quality of Life	
RAinDRoP	Rare Disease Research Partnership	A UCD partnership focused on bringing all stakeholders together to prioritise and undertake research on rare diseases (focused more on social care than medical research)
RD	Rare Disease(s)	Usually only abbreviated in writing
RDD	Rare Disease Day	Usually only abbreviated in writing
RDI	Rare Diseases Ireland	
RDF	Rare Disease Forum	This evolved from what was known as the Rare Disease Taskfoce. HRCI will run one Rare Disease Forum meeting a year
RDTRC	Rare Disease Technology Review Committee	This committee is responsible for: 1) reviewing proposals received from industry or expert groups in Ireland for funding of new products for rare diseases, or expanded indications for existing products for rare diseases; and 2) providing contributions to the development of clinical guidelines for Orphan Medicinal Products (OMPs) and supporting their implementation

Acronyms (continued)

Acronym	Acronym in full	Explanation
REC	Research Ethics Committee	
RPO	Research Performing Organisation	Sometimes used to refer to universities, colleges, or other organisations where research takes place
SFI	Science Foundation Ireland	
SLG	Shared Learning Group	We sometimes abbreviate our PPI Shared Learning Group to SLG
SMAB	Scientific and Medical Advisory Board	May also be called medical and scientific advisory boards or variations thereof
SORP	Statement of Recommended Practice	An accountancy term relating to best practice in how charities should report their annual accounts
SPHERE	Structured Population and Health Services Research Education	This is a population and health services research network connecting individuals working in research, policy, and practice. The SPHeRE programme supports health research through a PhD programme funded by the HRB
SSNO	Scheme to Support National Organisations	This is a funding scheme administered by Pobal on behalf of the Department of Rural and Community Development. It aims to provide multi-annual funding towards the core costs of national, community, and voluntary organisations in Ireland
THEA	Technological Higher Education Association	The equivalent of the Irish Universities Association for the technological institutes
TMRN	Trials Methodology Research Network	This is a HRB-supported collaborative initiative between a number of Irish and international higher education institutes and methodology centres. It aims to strengthen the methodology and reporting of trials in health and social care in Ireland

Acronyms (continued)

Acronym	Acronym in full	Explanation
ToR	Terms of Reference	Often used in relation to groups/committees that HRCI or others manage
UHI	Unique Health Identifier	Sometimes also referred to as an individual health identifier
YPAG	Young Persons' Advisory Group	Sometimes referred to in the context of PPI
#HealthResearchMatters	HRCI's hashtag	