



Charities & Researchers partnering for societal benefit

Guidance for charities, other civil society organisations, researchers, research institutions and funders, to achieve successful research partnerships

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- 1 [More Than Publications](#): Maximising Societal Benefit from Health Research. Report of the Irish Health Research Forum meeting November 2022, 2023, HRCI.
- 2 [Impact 2030](#): Ireland's Research and Innovation Strategy, 2022, Department of Further and Higher Education, Research, Innovation and Science.
- 3 [Reports and Data](#) Creating our Future, Government of Ireland.
- 4 [Strategy 2021-2025: Health Research – Making an Impact](#) Health Research Board.

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An introduction to the theme of achieving societal benefit through research

Recent years have seen a very welcome progression towards research being viewed as central to addressing societal challenges. In the context of this publication, when we talk about societal benefit from research, we are referring to research having impact for the health and well-being of patients and the public. Irish universities and the health service are beginning to reconsider how to measure research success. While research has long been driven by traditional academic metrics such as journal impact factors and successful research funding applications, the system is starting to adopt broader interpretations of research impact, such as whether it has led to changes to policy or practice. Funding calls, research awards and researcher CVs are all moving towards an expansion of the definition of research impact, to now include societal benefit.

This publication focuses on the value of charities and researchers partnering to achieve societal benefit (or impact) from research. In 2023, the Irish Health Research Forum made seven recommendations on this theme which included a strong emphasis on research co-creation with patients, members of the public, charities, and other societal partners¹. Both [Impact 2030](#): Ireland's Research and Innovation Strategy²; and the [Creating our Future](#) Expert Committee Report³, emphasise the importance of researchers engaging and partnering with civil society. The Health Research Board's (HRB's) [Strategy 2021-2025](#) also places a very strong emphasis on the meaningful involvement of patients, carers and the public in research as a pathway to more impactful research.⁴

The growth of public and patient involvement (PPI) in research

Irish health and social care research has seen particular progression in the involvement of people who may be impacted by that research, in what is referred to as public and patient involvement (PPI). The national PPI Ignite Network, funded by the HRB and the Irish Research Council, with co-funding from the seven universities at the centre of the Network, launched in 2021 and has been steadily changing research culture. The PPI Ignite Network provides leadership for PPI in research in Ireland, driving excellence and inspiring innovation, by building PPI capacity among all stakeholders and embedding a culture of meaningful involvement of the public and patients in research across Ireland.

- 1 The language of the non-profit sector is complex but here we use the term charity to align both with HRCI's name and the Charity Regulator. However, this publication equally applies to all civil society organisations, who often identify as community organisations, voluntary organisations, non-profits, NGOs, social enterprises etc.
- 2 [Patient and Public Involvement \(PPI\)](#) HRCI.
- 3 [Community and Voluntary Organisations to Benefit from Research Partnerships Funded by Irish Research Council](#) 2022, Irish Research Council.
- 4 [HRCI/HRB Joint Funding Scheme](#) HRCI.

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The role of charities in research

Charities⁵ and all types of civil society organisations have a very important role to play in achieving societal benefit from research. They are often particularly well placed to help ensure the relevance of research to patients and the public and to facilitate societal benefit from research.

Health Research Charities Ireland (HRCI) is supporting a community of over forty charities actively involved in health, medical and social care research. PPI is a core focus for HRCI, and it has been very active in supporting stronger PPI, both within its member charities and at a national level⁶.

Charities bring a very informed and broad patient/public perspective to research and can often facilitate individual members of their community to be PPI contributors. Building a partnership with a charity that represents and supports patients or other members of the public is a recommended approach for research groups who wish their research to achieve benefit for society. However, the needs of charities who become involved as research partners are often poorly understood by the wider research community.

Examples of funding schemes supporting charity-researcher engagement

Many funding schemes exist that facilitate the involvement of charities as collaborators or associated partners. This can be the first introduction for both sides of a potential partnership between a charity and a researcher. While some research awards allow for the development of a genuine partnership, most do not provide any budget for charity costs and once the funding is secured, the charity's involvement can be limited.

Through the Irish Research Council's funding programmes, which place a strong emphasis on partnerships, a total of 362 partnerships between civil society organisations and researchers have been supported since 2015, with an associated investment in excess of €9.9 million⁷. Involvement of civil society organisations in this way has facilitated co-design and has demonstrated great vision by the funder. While most of these awards do not provide any budget for charity costs (such as salaries or overheads), many charities in the health and social care space have benefited from the involvement in these schemes.

Some national funding schemes exist where charities can co-fund research. The HRCI-HRB Joint Funding Scheme, run as a partnership between HRCI and the HRB, is a progressive scheme that offers HRCI member charities the opportunity to co-fund research of importance to their communities with the HRB⁸. To date, 151 co-funded awards have been made, representing a total investment of €25 million. While this scheme is hugely valued by the participating charities, its purpose is to facilitate them in being effective funders of research, rather than partnering in the research (although there is strong charity influence on many of the successful projects).

At EU level, civil society organisations can lead grant applications and their participation is funded to the same level as research or industry partners. However, as Irish charities in the health and social care space have limited opportunities to lead or participate as equals in research grant applications nationally, they are not well primed to take advantage of European funding calls. Access Europe⁹, an initiative led by The Wheel to support civil society organisations to secure EU funding, is a valuable resource. To maximise its potential though, it needs to be paralleled with national opportunities for civil society organisations to build their capacity in leading and managing research grants and holding research budgets.

Why this guidance document?

The particular needs and perspectives of charities and researchers wishing to form partnerships have not been well captured or described. This is despite a growing number of resources focused on PPI and engaged research. In response to this and to wider positive momentum, HRCI and the PPI Ignite Network National Office came together in 2022 to run a workshop focused on charities and researchers partnering on grant applications. It was attended by charities, staff from the PPI Ignite Network, research funders and university research offices. The discussions at that workshop have strongly influenced this guide.

It emerged emphatically from the workshop that key to strengthening partnerships between charities and researchers is a mutual understanding of each other's perspectives and needs. For this reason, the subsequent sections of this guide provide insights into the perspectives of both charities and researchers – those at the coalface of partnerships. We then provide recommendations for both of these groups, as well as for research institutions and funders. We hope that this publication is just the start of a conversation that will ultimately lead to major benefits for people in Ireland and beyond.

10 By partnering in this context, we mean any activity that requires charities and researchers to both contribute time and resources to support the planning, undertaking, dissemination or translation of health and social care research. This could involve things such as being collaborators on a grant application, working together to facilitate patients or members of the public being involved in the research or combining forces to achieve impact from the research outcomes.

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What should a good partnership look like?

Partnerships¹⁰ between charities and researchers should ideally only be undertaken once both parties have considered what will be required of them and they have come to a mutual agreement on their commitments and expectations before, during and after a piece of research is undertaken. **In an ideal scenario, the partnership should begin prior to setting the research question and continue until the desired impact from the research is achieved.** Questions each party might ask of themselves and each other include:

- Have we shared values?
- Will we strengthen and add value to each other's work?
- Do we share an understanding about how the research will be managed and how the outcomes will be used?
- Do we share common goals and indicators of success (bearing in mind that it is never possible to fully predict the outcomes of research)?
- Have we discussed funding arrangements, does the research grant allow for what we have agreed and are the arrangements fair (or at least acceptable), to all involved?
- Do we share a common language about all aspects of the research?
- Do we understand each other's concerns and expectations about the research?
- Can we dedicate the time and resources to meaningfully undertake this partnership?
- Are the benefits from the partnership likely to outweigh the investment of time and resources that will be required?

Understanding the charity perspective

Why charities partner with researchers

All charities have a ‘charitable purpose’ from which their activities flow. Many charities with a focus on health and social care include research as a mechanism to achieve their purpose of improving lives. Research is an essential element of addressing unmet health and social care needs. When a charity is involved as a partner in research, the charity, and its community benefit from the generation of research evidence addressing questions that matter to them. This might answer questions about a health condition, lead to new treatments or influence health and social care policy and practice. The charity might also draw on research evidence to help understand the needs of its community, to shape its strategy, to secure additional funding for the services it offers or to underpin its advocacy work.¹¹ The shared sense of purpose that develops in researcher-charity partnerships can be mutually beneficial and motivating to both parties.

Charities frequently work with researchers to define research questions or sometimes bring research questions to researchers. They generally understand the importance of research publications, presentations at scientific conferences and other academic metrics. Ultimately however, charities want any research that they are involved with to lead to impact that has real benefits for people’s lives.

How HRCI member charities support research

Support PPI Communicate research to lay audiences

Use research to improve health and social care

Connect research stakeholders

Fund research Involved in research decision-making

Run research events

Support a patient registry

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25

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75

Based on the responses of 25 member charities to a HRCI survey in 2023

Examples of the challenges that can occur for charities

While charities have many examples of rewarding collaborations that lead to fruitful outcomes, there are also examples of charities having less-than-optimal experiences, not all of which are caused or can be solved by researchers. Understanding the challenges charities experience will lead to better future partnerships. Some examples include:

- Requests from researchers for involvement from charities in a grant application can occur last minute, reducing the likelihood of the charity having meaningful input in shaping the research and causing them operational challenges.
- Funding call requirements can pose challenges if, for example, partner application forms seek information on academic metrics that are not of relevance to charities.
- Research teams do not always inform the charity of the outcome of grant applications, particularly when a grant application is unsuccessful.
- There may be high demands on the charity's time over the course of a project, negatively impacting on their other activities.
- The charity may not be adequately involved in research decision-making as the project progresses.
- Administrative challenges can arise, such as delays in accessing allocated funding for the charity.
- There can be a lack of understanding of the weight of responsibility that the charity feels for the community they represent, particularly when asked to facilitate PPI.

For these reasons there can be many considerations for charities when deciding what research to get involved in.¹² Spending significant time on research grant applications that have an uncertain likelihood of success and are inherently risky if funded, may not be viewed as a priority for their board or supporters. On the other hand, however, a strong ethos to work relentlessly in pursuit of the charity's purpose can result in a reluctance to decline any opportunity.

Resourcing for charities

In general, charities are very under-resourced. Some, which have both the budget and ambition around pursuing research, have one or more people dedicated to research activities but many do not. Many charities are driven by volunteers and have no paid employees. Even for charities who have dedicated research posts, their time is likely to be stretched across many activities and relationships. The fact that some charities are themselves funders of research has perhaps contributed to a view that that they do not need to be resourced for their time on projects. Research teams may find it odd to consider why they would need to fund a funder. Charity research budgets, however, tend to be small and ring-fenced.

In Ireland, there are very few research funding schemes in which a charity can lead or be an equal partner and therefore, the financial and decision-making power almost always lies with the academic research team. It has also not been the norm for charities to be funded for the time and expertise that they contribute to research. For example, while a grant might fund the salary and overheads of a university-based research assistant to hold focus groups, the same grant is unlikely to fund the salary and overheads of a charity research officer to hold PPI workshops. Charities report that requests from researchers for their involvement is steadily increasing and many charities are likely to find that continued partnering in research projects is unsustainable without some or all of their costs and expenses being covered. Changing this will require a shift in mindsets among researchers, research institutions, funders, and charities themselves.

Understanding the researcher perspective

Why researchers partner with charities

Most researchers are passionate about the potential of their research to bring about positive change to the population at the centre of their research and broader societal benefit. To this end researchers often recognise the benefits of connecting with charities, particularly the deep understanding charities have of the real needs of the communities they support, which can help ensure that research is rooted in real-world issues.

Many charities can also facilitate PPI and have skills in research communications, particularly to patient and policy audiences. Researchers also value charities' expertise in using the outcomes of research to positively impact policy and practice. While it is hard to generalise, even some of the smallest charities can have wide networks of the people who, together, can bring about change – such as researchers, clinicians, policy makers, politicians, patients, or the people impacted by an issue.

Many researchers who partner with charities quickly see the benefits that it can bring beyond funding or a simple gateway to the charity's community. We are increasingly seeing researchers establishing strong and equal partnerships with charities, as they work together to achieve societal benefit.

Examples of the challenges that can occur for researchers

While many researchers have positive experiences of partnering with charities there remain many barriers and issues with which they must contend. Understanding these will lead to better future partnerships. Some examples include:

- Tight grant deadlines bring workload pressures on all sides, requiring an understanding of the priorities and resources of all involved.
- Researchers may be unaware that in some charities, board approval must be requested for involvement in any research proposal, which can take time.
- Charities may not be familiar with research funding call conditions, such as the narrow remit of a call or that costs for the charity may not be eligible.
- Researchers must comply with funder terms and conditions and with university financial processes and systems, thus limiting their ability to meet the hopes and expectations of charities.
- Spending the time required for optimal relationship building on a grant application with an uncertain outcome (typical success rates are 8%-20%) may not be viewed as a priority by researchers or rewarded within university structures.
- Researchers can be concerned about offering false hope for short-term outcomes or definite solutions.
- Most researchers have not received training in partnership building and or in the skills required to ensure that their research is translated into societal benefit.

Resourcing for researchers

Researchers are constantly juggling teaching, administrative, publication, grant writing, and other responsibilities. Grant deadlines come around fast and sometimes there is not enough time to dedicate to building long-term relationships with charities or for detailed discussions and thoughtful deliberations required before completing a grant application. Researchers who have teaching and/or clinical posts seldom receiving funding for their own salary through research grants and, therefore, do not have protected time to commit to a research programme.

1 [PPI Ignite Network Values and Principles Framework, 2022](#) Trinity PPI Ignite Office.

2 [Partner Database](#) Access Europe.

Recommendations for stakeholders in charity-researcher partnerships

Below we provide recommendations for important stakeholders: charities and other civil society organisations, researchers, research institutions and research funders. The PPI Ignite Network Values and Principles Framework¹³ offers an overarching framework for all these recommendations. It emphasises the importance of respect; trust; flexibility; transparency; empowerment & power sharing; collaboration and partnership; and equity & inclusion, in PPI and is also relevant in this context.

Recommendations for charities & other civil society organisations

- **Invest time in long-term partnerships with researchers and research institutions.** Identify leading researchers in your area at conferences, from publications and through the media and make contact with them.
- **Lay out your research priorities and what you can offer to research partners.** You might put this up on your website or develop a short document that you can send to researchers.
- **Complete a profile on the Access Europe website¹⁴.** Also seek out other portals of relevance to your research that will highlight your needs and offerings.
- **Request the information that you need to make an informed decision about a partnering opportunity.** This might include a draft grant application, information on eligible costs and expected time commitments. A standardised email requesting this information might be helpful for charities who receive many requests.
- **Consider any request in the context of your charity objectives, the needs of the community you represent and the resources you have available to you.** Doing preliminary work on the research priorities for your community will be helpful to your decision-making process.
- **Decide whether funding for your time, expertise and costs is unnecessary, desirable, or essential.** It can be a useful exercise to cost the time you will need to allocate to the research, even in cases where funding is not needed or available.
- **Check what costs are eligible under different research funding calls and whether it is most appropriate for you to be a co-applicant, collaborator, or other type of partner.** Agreements on funding allocations should be done during grant writing as they are very difficult to change later.
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- **Agree a memorandum of understanding with researchers at the outset of a project.** This should lay out your expectations from the research team, your commitment to them and agreements on costs and expenses.

✓ **Value your own expertise.**

Be clear in the knowledge and skills that your organisation can bring to a research project or initiative.

✓ **Understand the researchers' perspectives and limitations.**

They may have tight deadlines, budget restrictions or may not be used to thinking about research impact in the same way as you.

✓ **Respect researchers' expertise and do not attempt to influence the outcomes of a research project.**

While your input into a research question and study design can be very beneficial, care must be taken not to jeopardise the integrity of the scientific approach, even if the plan or outcomes are not what you had hoped.

✓ **Carefully consider all opportunities but don't be afraid to say no.**

For everything you agree to do, there is something else you can't do.

Recommendations for researchers

- **Aim for long term relationships with charity partners rather than last minute or sporadic communications.** Ideally the involvement of a charity in your research should happen prior to the setting of a research question and long beyond the completion of a project.
- **Find charities of relevance to your research.** The many avenues to do this include through umbrella organisations like HRCI and The Wheel, through engaging with PPI Ignite Network offices or by searching the Charities Regulator register of charities¹⁵.
- **Familiarise yourself with a charity's objectives and resources.** This will help you to understand what their perspective and challenges might be. Many charities have annual reports on their website providing such information.
- **Contact potential charity partners as early as possible in advance of a grant application.** Be aware that charities may need time to consider your request and often have to adhere to internal processes and timelines.
- **Aim to budget for a charity's costs and expenses when involving them in a grant application.** When funding is not possible, ensure that you have a frank conversation about this as early in the process as possible.
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- **Clearly lay out the value you can bring to the charity's community.** This is particularly important in a first contact with a charity and is more likely to lead to a successful partnership.
- **Engage with your research office (if you have one) well in advance of call deadlines.** This will allow time for them to advise on the most appropriate type of partnership, eligible costs for charities and the best mechanisms to make payments.
- **Invest time in writing lay summaries of your work that are jargon and acronym free and easily understandable.** Even if the charity staff or volunteers are familiar with your research, this will enable them to explain it more easily to their communities.
- **Ensure that the charity is kept abreast of developments through all stages of the research project.** Be upfront about grant application success rates, expected timelines and any known caveats to the research plan. Also make sure to inform the charity of the outcome of any grant application or research outputs in a timely manner.
- **Agree a memorandum of understanding with the charity at the outset of a project.** This should lay out your expectations of the charity, your commitment to them and agreements on costs, expenses and expected timeframes.

✓ **Be open to the expertise and value that a charity can add to your research.**

Academic and clinical research settings foster a perception of 'expertise' that is based on qualifications and hierarchy, which can require a mindset shift to move beyond.

✓ **Understand that a charity will feel a huge sense of responsibility to the community they represent.**

It will place them in a difficult position if the experience of their community, as PPI contributors or as research participants, is negative.

✓ **Be thoughtful about what you ask for from a charity.**

Keep the charity informed and involved as appropriate but also be mindful not to overburden them or to take their time from other important needs. Consider meeting them in locations and at times suitable for them.

✓ **Be mindful of power imbalances and strive for a mutually respectful relationship.**

Issues can arise, for example, when the research team hold the project budget, when a charity representative is a patient of a clinical researcher, or when different types of expertise are not valued equally.

✓ **Ensure that your conversations with a charity and their community are two-way.**

While you will be interested in their views on your research, they will be interested in a full picture of why you are undertaking the research and what you hope to achieve from it.

Recommendations for universities and other research institutions

- **Include a focus on research partnerships with charities and other civil society organisations, in all institutional strategies and plans.** This should be in addition to highlighting the importance of building relationships with members of the public and patients.
- **Include relevant charities in research events and conferences.** This can be a successful way to seed new partnerships.
- **Advise researchers on how to budget for a charity's time, costs, and expertise in grant applications.** When the funder does not allow those costs, advise researchers on the need for a frank conversation with the charity.
- **Develop a transparent process outlining the requirements of charity partners to be budget holders on a grant.** This particularly relates to instances where there is budget sharing written into a grant and a legal agreement may be required.
- **Simplify the process of transferring funds from the institution to charities.** Finance staff should be cognisant of the fact that charity finance functions may be managed by volunteers or part time staff and should aim to not create extra work or delays for them.
- **Recognise and reward researchers, through promotion and other mechanisms, for partnerships with charities and other civil society organisations.** These should be captured in metrics, to the same extent as industry partnerships.
- **Include information on the role and perspectives of charities in all PPI training for researchers.** This should be included in all relevant undergraduate and postgraduate curricula.
- **Provide training on charity partnerships for staff who have a role in supporting them.** This should include staff of research, finance, technology transfer and HR offices.
- **Invest in posts to support charity involvement with the institution.** These posts could be distinct or could be merged with PPI or engaged research support roles.

A Campus Engage policy briefing for higher education institutions on engaged research for impact provides additional, broader recommendations for consideration.¹⁶

Recommendations for research funders

- **In grant calls highlight when it would be of value to involve charities or other civil society organisations.** This should distinguish the role that charities play from that played by individual PPI contributors and should encourage early engagement.
- **Define how charity partners can be involved in a research grant application.** In parallel, relevant sections of the application forms, such as CV templates, should be tailored for non-academic partners.
- **Ensure that charity costs are eligible in all funding schemes for which a charity partner would be beneficial.** There should be an acknowledgement that work by a charity is not free and researchers should be encouraged to budget for their time and expertise.
- **Permit charities to receive an overhead allocation for projects in which they have a significant role.** The basic costs of hosting staff to support research are one of the most challenging for charities to fund and there should be parity for charities and universities in this regard.
- **Mirror the mechanisms of EU funding calls in Ireland, with regard to societal partners being equal to researchers and industry partners.** This will build capacity in charities to take advantage of European funding calls.
- **Any reporting requirements on charity partners in grant applications should be proportional to the funding received.** Funders should define charity reporting requirements and universities should refrain from adding additional requirements.
- **Discourage the culture of charities being requested to provide letters of support for projects that they are not directly involved in.** It should be made clear to applicants that such letters will not add value to their application and may, in fact, hamper it.

A Campus Engage policy briefing for funding agencies provides additional, broader recommendations for consideration. ¹⁷

Appendices

About Health Research Charities Ireland (HRCI)

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities active in health, medical and social care research, together representing over 1 million people in Ireland. Through support and advocacy, we represent their joint interests, to achieve our vision of improved lives through a united community of health research charities.

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. We are a national partner in the PPI Ignite Network and run a PPI Shared Learning Group for our member charities.

hrci.ie

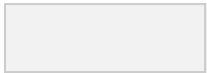
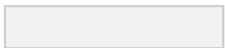
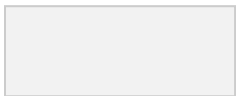
About the PPI Ignite Network

The PPI Ignite Network provides leadership for PPI in research in Ireland, driving excellence and inspiring innovation, by embedding a culture of meaningful involvement of the public and patients in research across Ireland. With seven Universities at its centre, ten national partners and over fifty organisations who are local partners with individual Universities, the Network's overarching aim is to build PPI capacity across research, public and patient communities.

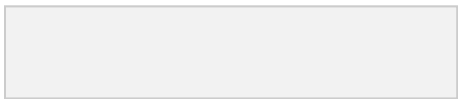
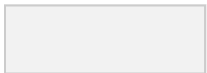
Funded by the Health Research Board and the Irish Research Council, with co-funding from the seven Universities at the centre of the Network, the Network develops and delivers PPI education and training, and facilitates shared learning opportunities. The Network also focuses on bringing about change in research and institutional cultures, to facilitate the public and patients to be at the centre of research decision-making. A central online hub of information and resources about PPI and Network communications activities support and connect researchers and PPI contributors nationally.

ppinetwork.ie

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The PPI Ignite Network is supported by the Health Research Board and the Irish Research Council.