

PPI in the HRCI/HRB Joint Funding Scheme: Case study of excellence

*Cystic Fibrosis Ireland/University of
Limerick: Exploring diet quality in Cystic
Fibrosis*

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About HRCI and its members

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities active in health and medical research, together representing over 1 million Irish patients. Through support and advocacy, we represent the joint interests of our 40+ members, working to improve health and prevent illness through research. We also fund and manage the Irish Health Research Forum, bringing together all stakeholders to improve health research in Ireland. It is our core belief that today's health research is tomorrow's healthcare.

The HRCI/HRB Joint Funding Scheme

The HRCI/HRB Joint Funding Scheme is a unique scheme that brings together members of Health Research Charities Ireland (HRCI) and the Health Research Board (HRB) to co-fund research projects of key relevance to member charities. For successful projects, the HRB contributes 50% of the cost of the project and the HRCI member charity contributes the remaining 50%. Very small charities currently contribute 25% of the cost and the HRB contributes 75%. The HRB makes an annual contribution of approximately €1 million to successful projects. Each award is worth up to a total of €300,000 (combined charity and HRB funding) for projects from 12 to 36 months' duration. Public and patient involvement (PPI) has been integrated as a fundamentally important aspect of the Joint Funding Scheme. The HRB includes specific questions about PPI in the application form and the Review Panel includes PPI reviewers who review the PPI aspect of applications. This case study presents an example of an application to the Joint Funding Scheme that was praised for its excellent approach to PPI.

1. Background to the case

The role of Cystic Fibrosis Ireland in the application

Cystic Fibrosis Ireland (CF Ireland) is a voluntary organisation that was set up by parents in 1963 to improve the treatment and facilities for people with Cystic Fibrosis (CF) in Ireland. Currently, its mission is to assist the development of the means to cure and control CF, to promote interests and the welfare of people with CF in Ireland, and to assume advocacy for them and their needs¹. As part of its work CF Ireland is committed to funding research to advance knowledge and understanding of CF. To this end, the charity participated in the 2019-2020 round of the HRCI/HRB Joint Funding Scheme and co-funded (with the HRB) a successful project designed and delivered by the University of Limerick on diet quality in CF.

As a patient representative organisation, CF Ireland prioritises the funding of patient-centred research and has a strong commitment to PPI. As Philip Watt, CEO of CF Ireland, states: "The inclusion of people with CF particularly through their patient group, CF Ireland, in all aspects of the project cycle, from project conception, design and methodology, analysis of results and dissemination, ensures outcomes that are of importance and relevant to the community."

The research project

The aim of this project is to explore diet quality in CF and its impact on disease and quality of life. The proposal sets out a mixed methods design, gathering data via food diaries and food frequency questionnaires to look at the dietary inflammation potential of the diet with health-related quality of life in CF. Online focus groups will also be conducted to explore drivers for current dietary patterns and enablers and barriers to eating a healthy diet.

2. Setting out the PPI approach in the application form

PPI is integrated as a core aspect throughout the application. This started with the approach to setting up the multi-disciplinary research team. The team is led by the principal investigator (PI), Dr Audrey Tierney, Senior Lecturer in Human Nutrition and Dietetics in the School of Allied Health, University of Limerick. She is supported by 5 co-applicants and 8 collaborators, including Dr Jon Salsberg, Senior Lecturer in Public and Patient Involvement (PPI), Ms Liz Jacques, Regional Development Officer with Cystic Fibrosis Ireland and TLC4CF (a charity affiliated with CF Ireland that aims to improve services and supports for people with CF in the mid-west region of Ireland) and a patient advocate with CF Ireland, Ms Caroline Heffernan. The overall PPI approach set out by the applicants is supported by the HRB-funded PPI Ignite Team in UL who are involved in the design of the planned PPI component of the project and will support the PPI work throughout the project.

The applicants incorporated PPI in their **research design and methodological approach (Section 2.5d²)** through basing the choice of some of their Patient-Reported Outcome Measures (PROMs) on a James Lind

¹ <https://www.cfireland.ie/about-us/cystic-fibrosis-ireland>

² Please note that we have used the section numbers from the 2019 application form, which may change in future rounds.

Alliance (JLA) priority-setting initiative³. Planned online focus groups with people with CF are also described in this section of the application. The applicants propose that questions for these focus groups be developed by researchers along with stakeholder input from the PPI collaborators on the team, to ensure the interviews will elicit information on the themes important to adults with CF.

The section on **project management (Section 2.5e)** of the application) also incorporates PPI. The applicants propose setting up a PPI advisory group to include representatives from the research team (including the PPI collaborators) and additional patient and health care representatives. The advisory team has a number of roles, including overseeing and advising on the management of the PPI aspect of the research, assisting in the design and delivery of the research (especially regarding the online focus groups with people with CF), ensuring the accessibility and appropriateness of the language used in patient information leaflets and consent forms, and taking part in the evaluation and dissemination of the research.

In the section on **public involvement in the research project (Section 2.5f)** section the applicants describe how their approach to PPI started well in advance of preparing the application by meeting with the CEO of CF Ireland and a patient representative. This led to the identification of diet in CF as a priority topic for further exploration. The multi-disciplinary research team, including PPI collaborators, worked together to refine the overall research question, taking into account the needs of the target population, as well as to select appropriate outcomes and enhance service user engagement. Within in this section the applicants describe how the PPI advisory group will have meaningful input into all stages of the research life cycle. The applicants stated that the principles of participatory health research⁴ will be used to inform how PPI representatives would be supported in the proposed research. This will be bolstered by the provision of training for PPI representatives via the annual University of Limerick PPI Summer School (which is open to anyone).

The applicants' **impact statement (Section 2.5h)** presents anticipated outcomes, clinical significance and impact on clinical practice. The applicants state that their PPI approach, through thorough consultation with people with CF, health care representatives and representatives of CF Ireland, will generate long-term impact on guideline development, practice change, and parental involvement in improvement of dietary quality in CF over the longer term.

Finally, the **dissemination and knowledge exchange plan (Section 2.5k)** includes a strong focus on PPI, with target stakeholders including people with CF and their families and patient organisations. The dissemination strategies proposed by the applicants are based upon continuous engagement with patient representatives and service users, involving a wide range of dissemination channels (newsletters, dedicated website, information seminars, and advocacy campaigns) and a layperson's summary for distribution to key stakeholders.

3. Strengths of the PPI plans in this application

This case study is an excellent example of how to integrate PPI throughout the lifecycle of the proposed research. PPI is incorporated from the very inception of the research study – defining the research topic – through to selecting suitable measures and devising questions for the focus groups, to project management, and finally to shaping the impact of the research and dissemination of findings. This approach means that PPI is a fundamental part of the overall research plan.

³ The JLA (<https://www.jla.nihr.ac.uk/>) is a non-profit-making initiative that brings patients, carers and clinicians together in Priority-Setting Partnerships (PSPs) to identify and prioritise the top 10 unanswered questions that they agree are the most important.

⁴ In participatory health research, service users are involved and participate in all stages of the research process. The entire research process is a partnership between service users and members of the research team.

Particular strengths in this approach are initiating PPI well in advance of preparing the application, the inclusion of PPI specialists and collaborators as formal co-applicants on the application, building on the results of a James Lind Alliance priority setting exercise to inform data collection measures, setting up a PPI advisory group to oversee and shape the PPI input into the proposed project, leveraging training for PPI representatives and securing ongoing PPI support via the PPI Ignite team at the University of Limerick⁵.

A notable feature of the application is the use of clear language and careful framing which signposted the PPI elements throughout. This made it easy for the PPI reviewer of this application to identify the PPI aspects, while at the same time demonstrating clearly how it was interwoven with the other elements of the proposed research.

4. Suggestions for future applicants

In addition to the good practice described in this case study, there are additional actions which new applicants to the Joint Funding Scheme (or other schemes) may wish to consider when preparing the PPI aspect of their applications.

1. It may be useful to kickstart plans for your application through an initial workshop or meeting, including the research team and patients, carers or members of the public that are relevant to your research. These same people might subsequently become part of your management team or advisory group. Together with Trinity College Dublin PPI Ignite, HRCI have produced a **toolkit for research charities to begin a PPI relationship**. Although targeted at charities, this toolkit includes useful information and guidance for anyone wishing to initiate a PPI relationship⁶. HRCI has also produced a **guide to developing a PPI strategy** (under our former name as the Medical Research Charities Group)⁷. This provides short, practical guidance on the things you need to consider in order to ensure a solid PPI plan.
2. The need for incorporating an inclusion and diversity approach to PPI is becoming increasingly important, and it would be worthwhile to set out relevant steps that applicants would take to help ensure their PPI approach is inclusive and welcomes diversity.
3. The cost of covering expenses for PPI contributors, associated with their activities on the projects, should always be included in the budget section of funding applications e.g. travel, food, accommodation, childcare, training etc. If possible, it is worth also considering offering a payment or token of appreciation for the time of the PPI contributors, which is a tangible appreciation for their input and can help with recruitment. Note that there may be implications for PPI contributors who are receiving benefits and it is a good idea to consult with them, along with your research office, to assess what form of reimbursement or payment is most appropriate.
4. Finally, it should be noted that PPI is not a one-size-fits-all endeavour, and not all aspects of the PPI described here may be suitable for use in other types of research such as lab-based research. Many of the HRCI member charities are skilled in PPI and the charity that you are submitting your application to might be able to advise or support your PPI. If you are based in an Irish university, your local PPI Ignite team will also be able to advise.

⁵ The PPI Ignite programmes and the National PPI Network, funded by the HRB and the Irish Research Council, were established to encourage greater public and patient involvement (PPI) in health and social care research across the island of Ireland.

⁶ Making a start: A toolkit for research charities to begin a PPI relationship. TCD PPI Ignite and HRCI, 2020: <https://bit.ly/HRCIPPItoolkit>

⁷ Developing a PPI strategy: A guide. HRCI, 2018: <http://bit.ly/HRCIPPIguide>

5. Further information

For further information on the work of HRCI on PPI and the HRCI/HRB Joint Funding Scheme, please contact Dr Sarah Delaney, Research Support Officer, Health Research Charities Ireland, email sarah@hrci.ie.



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