

Final Report Executive Summary



HSC R&D Division Final Progress Report

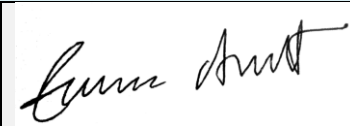
Final Reports should be submitted via electronic copy to HSC R&D Division within 6 weeks of the request. The report should be completed on the attached form in clear typescript. Please extend boxes as required. Please adhere to any word limits. These reports may be subject to external peer review.

Details from the Final Report may be placed on the HSC R&D Division website and shared with appropriate key stakeholders or members of the public.

HSC R&D Division Award Details

HSC R&D File Reference	STL/5562/19
HSC R&D Funding Scheme	PPI in Research Support: Small Grant Scheme
Project Title	Fostering partnerships between cancer researchers and people affected by cancer
Award Holder Name (Employer)	Dr Emma Allott Queen's University Belfast
Host Research Organisation	Queen's University Belfast
Award Duration	10 months
Award Start Date	01.02.23
Award End Date	31.12.23
Name of Lead Supervisor: <i>(only applicable to training awards)</i>	

Signature

Award Holder Signature:	
	Date: 10/04/24

Evidence Brief

(1 page: which may be used for dissemination by HSC R&D Division)

Why did we start?

(The need for the research and/or Why the work was commissioned)

Our Irish Association for Cancer Research (IACR) members commonly identify challenges around understanding how best to integrate PPI in their research, particularly for those in basic biomedical science which is the majority of attendees at the annual IACR meeting. To address these challenges, our goal was to bring together cancer researchers and people affected by cancer, in order for each group to learn from each other, in order to enhance PPI engagement in cancer research.

What did we do?

(Methods)

We held a 3-hour PPI Workshop, aimed at early career cancer researchers, at the 59th IACR Annual Meeting in Athlone, Westmeath. We invited people with lived experience of cancer as well as cancer researchers with experience of engaging PPI in their research to participate in this workshop as speakers and as round table discussion leaders. We collected feedback from round table discussions of the challenges around engagement with PPI as a biomedical cancer researcher. We hosted a PPI Stand for the duration of the 3-day IACR meeting, where cancer researchers could chat informally to PPI representatives in their own time. Finally, we competitively awarded a £500 seed funding voucher to one IACR member to support them engaging PPI in their own research.

What answer did we get?

(Findings)

We observed a keen interest from cancer researchers in engaging PPI in their research, evidenced by full attendance at the workshop and constant interaction at the PPI stand throughout the meeting. Thematic analysis of our PPI workshop discussions revealed four main themes. The first was around training requirements, where researchers highlighted a need for adequate training for scientists in relation to how to approach difficult topics with PPI. The second was around the difficulty in finding appropriate forums to identify PPI for rare and childhood cancers. The third was around the inclusion of PPI in lab-based research projects and how researchers felt this can often feel tokenistic instead of fruitful. The fourth was how to engage PPI at a late stage of a research project, and what sources of funding or resources are available.

What should be done now?

(Practice/Policy Implications and/or Recommendations)

Overall, the main barrier to engagement of PPI by cancer researchers was found to be around communication about available resources. Cancer researchers often felt they either lacked training or support which might well be available to them, but they were unaware of how to access it. We believe that this might highlight a need for more publicizing of training and funding opportunities, particularly targeted at basic biomedical science researchers as a group that may find PPI engagement particularly challenging. Furthermore, targeting early career cancer researchers may have the biggest impact on future integration of PPI in biomedical research.

Final Report

(no more than 20 pages)

Please structure the report using the headings below

- **Background**

There is increasing recognition of the importance of meaningful and inclusive engagement of individuals with lived experience of cancer, their carers and advocates, as well as members of the public in cancer research. Engaging PPI as the end users or stakeholders in the research has positive implications across the research cycle, from maximizing the relevance of the research question to ensuring transparent and accessible dissemination of findings. There is also benefit to the community of individuals with lived experience of cancer, as patients engaging in PPI report feeling empowerment and self-confidence (Brett 2014). As a result, an increasing number of funding bodies now require evidence of meaningful PPI engagement early in the application development process. As a result, scientists are now more keenly aware of the benefits of engaging PPI in their research.

The Irish Association for Cancer Research (IACR) is an All-Ireland non-profit organisation for cancer researchers across all disciplines, the largest of its kind on the island of Ireland. The IACR hold an annual meeting to share latest advances in cancer research, and this meeting is attended by cancer researchers of all stages from all universities across the island of Ireland. IACR members commonly identify challenges around understanding how best to integrate PPI in their research, particularly for those in basic biomedical science (Connor 2023) which is the majority of attendees at the annual IACR meeting. As such, the IACR annual meeting served as an appropriate platform to gather a large number of biomedical cancer researchers together in the same place, in order to deliver our PPI initiative. Many attendees at the IACR annual meeting are early-career researchers, and the first day of the meeting is targeted specifically at this group. Introduction to and engagement with PPI early in the careers of cancer researchers will break down some of the barriers around incorporating PPI in research for next generation, as this is arguably the demographic of researchers that will have the most impact on the future integration of PPI in biomedical research (Biggane 2019).

- **Aims and objectives**

The overall aim of this project was to bring together cancer researchers and people affected by cancer at the all-Ireland 59th Annual Meeting of the Irish Association for Cancer Research, held in Athlone, Ireland from 22nd-24th February 2023. The objectives were to provide an environment for collaborative discussion in the form of an interactive workshop and stand, and to foster new partnerships into the future through seed funding.

- **Methods**

Of 242 registered attendees of the 59th IACR Annual Meeting, 10 were PPI registrations. Of these 10, three were from Northern Ireland and were directly funded by this grant, including their travel, meals and accommodation and a daily compensation rate of £100 per day for time and expertise. For our workshop speaker we allocated an additional £100 (in the form of an Amazon voucher) to compensate them for their time preparing the presentation. These individuals participated in the following activities:

PPI workshop

The session opened with a welcome from our workshop facilitator, an individual with lived experience of cancer, who introduced four short (15 minute) talks from our PPI contributors. We considered that many attendees of the workshop had no experience of PPI and therefore our four speakers offered insights from different angles, including one individual with lived experience of cancer who shared their personal story,

one individual with experience of advising others how to integrate PPI into lab-based research (from a PPI organisation), one early career researcher with personal experience of working with PPI in their PhD project, and finally an individual with research experience in engaging with ethnic minorities in PPI. This was followed by a short lunch break and then a round table discussion session comprising 8 round tables, each with two leaders (one with lived experience of cancer and another with experience from the perspective of engaging PPI as a cancer researcher). We also had one scribe at every table to record notes of participant experiences and feedback regarding the challenges of engaging PPI as a cancer researcher particularly in biomedical science. Before the conference, we had held a video conference including our PPI participants to agree themes for round table discussions, and decided to keep it simple. There were four themes, 1. Why involve PPI?; 2. What is PPI; 3. How to involve PPI; 4. When to involve PPI. Workshop participants rotated after every 20 minutes to ensure all workshop participants experienced all four themes.

PPI Stand

The Stand was manned for the duration of the 3-day meeting on a rotating basis, with two PPI representatives always present. Cancer researchers in attendance at the meeting could interact with the PPI representatives informally during coffee breaks and poster sessions. The PPI representatives had leaflets from various PPI organizations to help overcome the challenge of making the first step towards engaging PPI in cancer research – finding a suitable PPI contributor.

PPI Seed Funding

We advertised seed funding to financially enable cancer researchers to meaningfully involve people affected by cancer in their research via the IACR website and social media and received two eligible applications. The winner was selected following peer review by the IACR Senior Council. The seed funding awarded will be used at the upcoming ACORN (All-Ireland Children's Oncology Research Network) event in Belfast (~April/May time, date TBC) to bring a patient to speak at this event.

- **Personal and Public Involvement (PPI)**

We developed the workshop in tandem with our PPI contributors, and the workshop facilitator was a person with lived experience of cancer. This ensured PPI engagement throughout the process, from speaker selection to round table discussion themes, to analysis of the findings from the workshop.

- **Findings**

Workshop discussions centred around the four preselected discussion points, with the first being 'why involve PPI?'. Early career researchers mentioned the benefits of integrating PPI in their projects, and mentioned that PPI engagement helps them balance scientific jargon and effective communication in their work. The next topic was 'what is PPI?', and workshop participants tended to discuss the difference between PPI participation and PPI engagement, detailing how it is key for PPI to be actively involved rather than passively obtaining information about the project. The third topic was 'how to involve PPI', and participants understood that the easiest approach would be to tap into existing PPI networks across the country. Participants emphasized the importance of incorporating PPI at an early stage of the research, highlighting the benefits of developing a lasting relationship between researcher and patient that could continue throughout the researcher's career. Maximizing transparency between researcher and PPI was noted to be of great importance to build trust in the relationship, as was regular communication. The final theme was 'when to involve PPI', and a substantial number of groups again highlighted the benefits of bringing in PPI activities as soon as possible, particularly in project design and conceptualization. However, workshop participants highlighted a challenge around getting PPI input at an early stage, as the majority of funding applications are unsuccessful and the project may never get off the ground. This serves as a deterrent for early career researchers, who do not want to be a nuisance to patients, constantly contacting them for input on funding applications that may very well not be successful.

Scribe notes from the workshop were transcribed digitally and used for thematic analysis, with the following themes identified: The first was around training requirements, where researchers highlighted a need for adequate training for scientists in relation to how to approach difficult topics with PPI. Engaging patients in discussions about their lived experience with the disease could bring up difficult emotions and memories. Researchers felt unprepared and apprehensive in reaching out to patients due to this concern. Most were unaware of training events of support for building the required communications skills and knowledge of support systems that patients could be directed towards, and highlighted the need for training in this area. The second theme was around the difficulty in finding appropriate forums to identify PPI for rare and childhood cancers. Despite the existence of forums and advocacy groups, researchers expressed their concern that finding patients / patient advocates for rare cancers and childhood cancers would be difficult. The third theme was around the inclusion of PPI in lab-based research projects and how researchers felt this can often feel tokenistic instead of fruitful. Researchers were apprehensive in the inclusion of patients in their lab-based research and felt that it was often a 'tick the box' exercise instead of fruitful for both researcher and patient. Researchers felt it challenging to make basic research engaging and patient friendly, highlighting that they felt there was a fine line between disseminating research to a lay audience and belittling a group by underestimating their level of expertise. It was noted that some patients have extensive knowledge in addition to their lived experience of their disease, which can be underestimated by researchers thereby preventing active collaboration between researcher and patient. Therefore, getting the balance right was an area of substantial concern to researchers. Finally, the fourth theme that emerged was how to engage PPI at a late stage of a research project, and what sources of funding or resources are available. Often students come to a project that is already in motion, and therefore they lose the opportunity to engage PPI at the conceptual stage. Many later stage PhD students felt that it was too late for them to engage PPI at that late stage of their project.

Finally, we noted that we received only two applications for seed funding to engage PPI in research, despite highlighting this funding opportunity at the time of the workshop and via mailing lists after the event. This may further exemplify the hesitation of many IACR members to newly engage PPI in projects that are already running.

Although we provided a QR code link to an online feedback form at the workshop, we received very little feedback. The little feedback that we did receive was overwhelmingly positive, including '*Excellent speakers. I liked the diversity of the talks and how they covered many aspects and perspectives of PPI during the workshop*', and '*As an early career researcher, my take home points were that in order to start PPI it is important to establish a relationship that is full of trust, and a lot of feedback and input that goes back and forth between the researcher and the PPI advocates, in order to enhance the quality of the research and to drive it towards a more patient focused setting*'. Topics suggested for future events included tokenism, how to approach sensitive topics and training on practical ways to include patients in non-translational/fundamental research.

- **Conclusion**

Excellent attendance and engagement at the PPI workshop highlighted that early career researchers understand the importance of PPI and have a keen interest in this area. However, they highlighted their perceptions of the challenges in actively involving PPI in their research. Early career researchers tend to be apprehensive of approaching individuals with lived experience of cancer for fear of upsetting them, or in case they appear to be tokenistic. Many also feel that their project is too far advanced, and/or that they have no funds to engage PPI effectively.

- **Practice and Policy Implications/Recommendations**

Funding opportunities for engaging PPI in research should be more visible, using multiple platforms including social media. Basic scientists and early career researchers should be targeted as this is the group that highlight particular difficulties in engaging PPI in their research.

- **Pathway to Impact**

A publication is being prepared, entitled “Assessing the Barriers to Effective PPI Involvement Amongst Early-Stage Cancer Researchers on the Island of Ireland”, targeted at the BioMed Central journal ‘Research Involvement and Engagement’, an interdisciplinary, health and social care journal focussing on patient and wider involvement and engagement in research, at all stages. The paper is expected to be submitted by summer 2024.

- **References**

Biggane, A. M., Olsen, M. & Williamson, P. R., 2019. PPI in research: a reflection from early stage researchers. *Research Involvement and Engagement* , 5(35), pp. 10.1186/s40900-019-0170-2.

Brett J, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient*. 2014;7(4):387–95. <https://doi.org/10.1007/s40271-014-0065-0>.

Connor AE, Hughes C, Schäfer L, McNally L, Raw DO, Bahramian K, Carr B, Dunne IH, Lysaght J, Toole SAO, Simpson JC, Perry AS. Involving patients in healthcare research is well documented but can it work in lab-based research? *Res Involv Engagem*. 2023 Oct 12;9(1):90. doi: 10.1186/s40900-023-00500-y. PMID: 37821914; PMCID: PMC10568930.

- **Relevant Logos**