

Evaluation of HRB public review pilot – summary

November 2017

This is Bob

Bob has an interest in health.

Bob wants to share his opinions with health researchers.

Bob becomes a public reviewer for the Health Research Board.

Bob is smart.

Be like Bob



This is Jane

Jane knows that one day she might become ill.

Jane wants to get involved in health research to improve future healthcare.

Jane becomes a public reviewer for the Health Research Board.

Jane is smart.

Be like Jane



Acknowledgements

The HRB wishes to acknowledge the interest of people in Ireland in this public review process. The response to our media campaign was astounding and the public reviewers who took part in the pilot made an invaluable contribution. We apologise to the many who were not selected. Many thanks also to the researchers who provided feedback to the HRB and the public reviewers.

Finally we would like to thank the NIHR Central Commissioning Facility and the NIHR Evaluation, Trials and Studies Programme for their advice and access to their materials.

1 Introduction – Public and Patient Involvement (PPI) in research

Public and patient involvement (PPI) happens when individuals meaningfully work together across the full research cycle. This can include governance, priority setting, and conduct of research, or sharing and applying the resulting knowledge. By ‘involvement’ we mean the active involvement of people who use services, carers, or the general public with researchers when making decisions about a research project. The starting point is that PPI improves the relevance of research questions, the quality, acceptability and feasibility of research conduct, and the likelihood of uptake of research outputs. It also increases public accountability for taxpayers’ money.

1.2 Health Research Board and PPI in research

The Health Research Board (HRB) is the lead agency in Ireland supporting health and social care research. The *HRB Strategy 2016–2020, Research. Evidence. Action.* sets out the role of the HRB in building a strong enabling environment for health research in Ireland. Within this lies the responsibility to provide leadership to shape the review, conduct and governance of research, including a commitment to develop and promote PPI within the HRB and HRB-supported projects and programmes.

In February 2016, the HRB carried out an online survey of Irish researchers and members of the general public, with the aim of starting a conversation about PPI and to gain a greater understanding of the best way the HRB could support the development of PPI in Ireland. Out of this came two key actions for the HRB:

1. **Development of a competitive funding call for the PPI Ignite Awards** to enable higher education institutions to integrate PPI into health research so that it becomes part of the culture and structures of the institution. Five awards were made in June 2017.
2. **Development of a public review pilot scheme to give researchers dedicated feedback on the quality of the PPI in their application for health research funding.** This summary outlines the evaluation of the public review pilot.

1.3 Where does the public review pilot fit into the HRB’s plan for PPI?

Since 2014, all HRB applications have included a question on PPI, without making it mandatory or part of the assessment criteria. This marked the first step in our effort with the commitment to develop our approach in a step-wise fashion (summarised in Figure 1.1 below). As a second step, the HRB wanted to provide more detailed and specific feedback from public reviewers on the PPI section of funding applications to help researchers develop their skills in PPI. The aspiration of the HRB’s PPI implementation plan is that eventually PPI reviews will be fully integrated in the scoring criteria of some funding schemes and may therefore influence funding decisions.

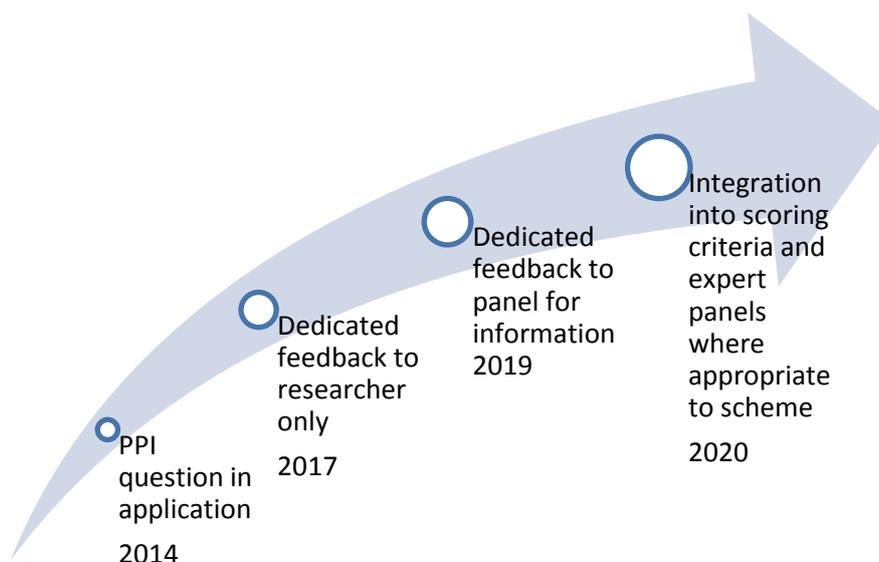


Figure 1.1 Summary of step-wise activities to integrate PPI into HRB review process

Introducing a public review pilot scheme was a logistical challenge for the HRB. No research funder in Ireland had attempted a similar approach previously. So in the absence of any Irish information, it was difficult to estimate the level of interest from potential public reviewers, or to get an understanding of the diversity of lived experience the interested reviewers would have.

To address this it was decided to pilot the public review for the Investigator-Led Projects (ILPs¹) 2017 and evaluate the pilot before agreeing whether to integrate the public review process in additional schemes. We were conservative in our estimation of what we could achieve for the pilot. We set a target for the pilot to engage enough public reviewers to provide feedback on a minimum of 50 ILP applications. In the end, public reviews were completed for 56 (42%) of the ILP applications.

For the purposes of the pilot, the public reviewers provided feedback to the research applicant, but not to the international expert review panel. There were no public reviewers as members of the expert panels making the funding recommendations.

The main aim of the pilot was to find out if we could carry out such a public review as planned, and also if members of the public and researchers would accept it. A secondary aim was to provide feedback to a number of researchers on how they could improve PPI in their research proposals. At the end of the pilot we assessed the outcome.

¹ The Investigator-Led Projects support the creation of new knowledge that will help to address the major health challenges in society and have an impact on tomorrow's healthcare.

2. Evaluation findings

The 2017 HRB public review pilot marked the first time an Irish research funder (public or voluntary) has attempted to incorporate a public review alongside the scientific review of research applications across a broad spectrum of research questions, disease areas and types of research. The findings from the evaluation clearly show that the public reviewer pilot scheme was a success from the perspectives of the HRB, the public reviewers and the researchers. The pilot allowed the HRB to test the practical aspects of a public review as well as the acceptability of the process for public reviewers and health researchers. The chosen funding scheme, the Investigator-Led Projects (ILP), represents a broad spectrum of health research.

We employed a full-time PPI Coordinator who managed all aspects of the review process. Public reviewers said that having a central coordinator whom they knew was valuable. They had built up a relationship with this person both before and after the training session. They found it especially helpful to know that they had someone to contact if they had difficulties.

The following sections highlight the key learnings from the evaluation.

2.1 Recruitment of public reviewers

- Radio was the most successful and cost-effective advertising method for recruiting the public to the public review pilot. Email was the preferred method of communication for 94% of potential public reviewers. Six per cent of applicants preferred post or telephone for contact with the HRB. These methods of communication were much more time consuming than email.
- An unanticipated high number of people (900) submitted expressions of interest. A total of 448 people filled in the longer application form within a short period of time. This shows a strong appetite for this type of initiative.
- The majority of people (391/448) submitted an application directly to the HRB rather than through the 'register my interest' option.
- Applications were received from 25 of the 26 counties in Ireland, suggesting that the recruitment plan succeeded in reaching a nationwide audience.
- Applicants were from a diverse educational and professional background, with the majority in full-time employment or retirement.
- The majority of applicants were motivated to participate for societal reasons, such as for the greater good of society or to improve the health service. A third of applicants were motivated to apply for personal reasons, such as general interest, time available, or to keep mentally active and try new experiences.

2.2 Development and usability of forms and database

- We used a classification system for categorising the lived experience of public reviewers developed in the UK by the National Institute of Health Research. This was a useful way to match reviewers to research proposals.
- Potential public reviewers were asked to complete an application form. The main feedback about the form content was that we should explain better the scope and objective of the pilot, what type of person we were looking for, and also improve the ways we collect information on reviewer backgrounds.

- From a HRB perspective, the application form provided enough information to match reviewers to a research application.
- Public reviewers were given a form to guide their review of applications. The application review form prompted reviewers to comment on the most important sections of the application forms, such as the lay summary, relevance of the research question and areas for improvement for PPI.
- A small number of public reviewers felt that some of the questions on the form were repetitive or confusing, and could be improved.

2.3 Training and support

- Forty-seven of the 57 public reviewers were divided into two groups and attended the training workshop before taking part in the review. All but one were pleased with training, reporting that it helped them understand their task better.
- Seven reviewers contacted the HRB for additional support once the review process was underway, and the majority of their queries related to clarification of questions on the review form.
- 97% of the reviewers felt that the support provided to them during the review process was sufficient (rated as excellent, very good or entirely adequate).
- Only two reviewers made suggestions on how to improve the support.

2.4 Public review process

- Matching reviewers to ILP applications was done in two groups after the completion of each workshop. This proved to be straightforward for the first group where there was a larger ratio of reviewers to ILP applications. The match for this group was based primarily on the areas of health interest indicated by the reviewer.
- For the second group there was a lower ratio of reviewers to available applications and the matching process took longer. The match for this group was based primarily on the areas of health interest indicated by the reviewer and more general statements of interest in the application form.
- Closely matching reviewers to applications may be more acceptable to the reviewers even if it does not have an effect on the quality of the review.
- There was a very high completion rate of 98% for submission of reviews from public reviewers. This compared to the not unusual completion rate of 85% for the scientific reviewers.
- Just over a third of the reviewers requested hard copies of the research proposal and associated review documents to be sent by post. Two reviewers submitted hard copies of their review, which required transcription. While this was possible for the small pilot, it was time consuming and would be difficult to replicate on a bigger scale.
- For the most part, payment of public reviewers was efficient and occurred within four weeks of submission of the review.
- As in the scientific review, some public reviews were more detailed and constructive than others.
- All researchers who completed the survey agreed that they would be willing to take on board suggestions from the public reviewers; half of these researchers reported that they would revise their application accordingly.
- The majority of the researchers (61%) reported that the feedback would help improve the lay summary. However, researchers felt that the public reviews of their applications would not assist in the recruitment of patients where applicable.

- A quarter of the researchers reported that the public review for the ILP application was beneficial for developing future proposals.

3. Conclusion

In conclusion, the public review process worked well. The process was valuable because it also highlighted some improvements that could be made if the pilot is extended to other funding schemes in the future. The HRB now needs to consider the information provided through the pilot, and weigh up the benefits and opportunity costs of extending the pilot to other HRB schemes. The lessons learned in the pilot will help the HRB to make a decision on:

1. Whether to proceed with a public review process in the future
2. If a public review would add value to an existing review process; and
3. How best to go about it.