

Guidance for Public Reviewers of Research Funding Applications to the HRB¹

¹ This form has been adapted from the NIHR Guidance for public reviewers of research funding applications to: PRP, i4i, PGfAR and RfPB programmes, with the permission of the NIHR Central Commissioning Facility

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1 Public and Patient Involvement (PPI) in Research

The Health Research Board (HRB) promotes the active involvement of members of the public and patients in the research that we fund. Public and patient involvement in research means that the public and patients are involved in planning and doing research from start to finish and help tell the public about the results of research. PPI, as defined here, is distinct from and additional to activities which raise awareness, share knowledge, and create a dialogue with the public, and it is also distinct from recruitment of patients/members of the public as participants in research.

2 Support for reviewers

Thank you for accepting our invitation to review a research *funding application*.

This guidance document aims to help you:

- understand the task of reviewing.
- successfully complete a review.

A Public Review Glossary is provided to help clarify the meaning of some of the terms used in the guidance notes and Public Review form. Terms that are included in the glossary are written in underlined blue Italic.

3 How the review process works

Reviews are an important part of how decisions are made about what to fund or what not to fund.

Reviews:

- inform the decision-making process of research programme panels.
- provide feedback to the people who have applied for funding including an assessment of the strengths and weaknesses of their application.

There is some variation in the review process between different HRB funding schemes, but the following flowchart gives a basic overview of how the review process works.

Researchers

Submit a *funding application* to a Research Programme.



HRB Programme Team

- Check the application meets all the basic <u>criteria</u> of the programme.
- Allocate the application to peer and public reviewers.



Peer & Public Reviewers:

Provide independent assessments of the application

- Reviewers provide written comments on the application in their review form.
- <u>Peer Reviewers</u> provide an overall score and public reviewers provide an overall rating.
- Applications are short-listed based on the average Peer Review score.
- Comments from peer reviewers and public reviewers relating to their application will be provided to all applicants.
- Short-listed applications will have the opportunity to respond to the public reviewer comments as part of the applicant response stage of review.



Research Programme Panel:

Use peer and public reviews as part of their decision-making process

- <u>Panel reviewers</u> will have sight of both the public review, alongside the scientific peer reviews, as well as the applicant team's response, thus it will inform the review of each application.
- At the end of the panel meeting, a final score is collectively agreed for each application and then they will be ranked according to score.



HRB Programme Team:

Process both successful and unsuccessful applications

• The lead researcher of every application funded or not, will be sent copies of any peer, public and panel reviews of their application – all the information about the reviewer (e.g. name) will be deleted from the review before it is sent to the researcher.



HRB Board Approval:

The Board of the HRB approve (or not) the funding recommendations of panels

• It can sometimes take a few months between an application being recommended for funding and the research starting. This could be for any number of reasons such as: budget issues or other agreements that need to be in place before a contract can be issued or it may be that the researcher is not quite ready to start working on the research.



Researchers

Funded research begins.....

4 Fee and expenses

We offer a standard payment for completing and returning the review to the HRB. Once you have returned your completed review to the HRB, the HRB will send you a form where you will be able to enter the payment due to you for completion of the review. It will take **approximately 4 - 5 weeks** for the HRB to make the payment to you after the deadline for review. At particularly busy times for our finance office, it can take longer. The HRB are required to apply tax to payments and we will need to report it to Revenue. The level of tax you pay will depend on your own personal situation. For more information on fees and expenses please see the HRB's public payment guide.

5 Confidentiality and conflicts of interest

You must treat the application you have agreed to review as <u>confidential</u>. This means that you may not discuss any aspect of the application or the assessment of the application with anyone else. If you think you need to discuss the application with someone else you must first seek permission from the HRB by contacting the PPI team by email ppi@hrb.ie.

You must follow high standards of honesty during the review process. If you receive or print a hard copy to work from, we ask you to either shred the documents when the task is completed or send them back to the HRB and we will <u>reimburse</u> postal expense through the expense form.

Please check with the HRB if you think you may have a <u>conflict of interest</u>. For example, do you know anyone on the research team personally? Have you been involved in developing this application?

6 What we need from your review

Your review is written from your <u>perspective</u> as a member of the public, informed by your knowledge and experience as a patient and/or carer and as an actual or potential user of health services.

It is important to note the difference between 'Public and Patient Involvement' in research and 'Participation' in research. Public and Patient Involvement in Research is where members of the public or patients are actively involved in research projects and in research organisations. Participation in research is when people take part in a research project.

Examples of Public and Patient Involvement include:

- Being co-applicants or collaborators on a grant application;
- Involvement in identifying research questions;
- Being part of a project Steering or Advisory group to direct the research;
- Helping to carry out the research, for example, through doing interviews with research
 participants, assisting with the development of patient information leaflets or other research
 materials or helping to disseminate research findings.

Examples of participation in research include:

- Being recruited to a clinical trial or other research study as a research participant;
- Answering a questionnaire or participating in a focus group to answer questions to help researchers answer a particular research issue.

The parts of an application that we particularly value your comments on are:

- Is the plain English summary of the funding application easy to understand? Could it be improved?
- In your opinion, will knowing the answer to the research question make a difference to real people? (now or in the future)
- How appropriate are any plans for public and patient involvement (PPI) in the research application? What difference will it make? Applications that are looking at health (specific diseases, the prevention of ill health or promotion of good health) or health services (e.g. delivery of care and treatment in hospital, primary care, General practice) should have patients or the public involved in the research. While different research projects will lend themselves to varying levels of PPI across the lifetime of the project, it is the responsibility of the applicant to clearly explain the PPI approach taken in the context of their research.
- How could the researchers improve their plans for PPI in their research?
- Have the applicants included any money for public involvement activities in their overall budget?
- If the research involves patients, do you believe people would be willing to take part?
- How would you like to hear about the outcomes of this research
 – for example Media interview,
 public talks, through your health provider if relevant, etc.?

For some examples of reviewer comments, please see 'Section 12: What makes a good public review?' Remember, we are getting a range of reviewers to comment on each application, including those with professional and scientific expertise. What we need from you is your perspective on how well they have included people who are most likely to be influenced by the research, or how they could improve *public and patient involvement* in their research.

7 Getting started

A research funding application can be anything from under 50 to well over 100 pages in length and it often includes <u>annexes</u>, supporting documents, CVs, charts and letters of support.

Before you complete the online review form you will have to read and find your way around the application. How you approach this task is up to you. However, here are a few tips from experienced public reviewers:

- If you start by reading the plain English summary, it can give you a useful overview of the
 application and ideas about what to look out for elsewhere. If it does not, then it may reflect a
 badly written plain English summary
- Applications can seem heavy and difficult to get through. It can be helpful to break down the
 review task into smaller chunks over a number of days. This gives you thinking time too. You may
 need to read some or all of the application several times, before and whilst you are completing
 the review.

- It's impossible to say how long it takes to complete a review. Like most things, the more reviews you do the easier and quicker it gets to navigate through the documents and the process. However, some applications will just be more complex than others.
- You could spend hours looking for information and exploring the things that an application makes you realise you don't know. However, don't lose sight of the fact that we have asked you to do the review because of your personal knowledge and experience as a patient, service user, carer or interested member of the general public. Keep your focus on the questions that are asked in the review form and remember your review is important from the 'public or patient' perspective so you do not need to know any details about the scientific aspects of the application. The peer reviewers will make sure that the researchers will do the research to a high quality.
- It may help you to think of yourself as a 'critical friend'. Someone who is encouraging and supportive, and who comments honestly and <u>constructively</u> about weaknesses and problems, as well as strengths and successes. Style and tone are important. Significant comments can be missed or dismissed because of an apologetic or an aggressive sounding remark. It is OK to disagree with the researcher, as long as it is in a constructive manner.
- Public reviewers are welcome to suggest rephrasing of sentences or redrafting of the lay summary. Researchers will welcome your comments.
- Single word answers are not helpful. Researchers who will read and use your feedback don't just want to know what you think. They also want to know the reason or reasons why you think it. For example, "On the basis of my experience as a carer of a person with motor neurone disease, I would suggest that the amount of home support that a family gets is the key question for carers and not how often the patient attends the clinic...", or "In the absence of any budget for PPI in this application it is difficult to imagine how the researchers would be able to include PPI in the research team in the way they have suggested".
- The rating that you give should be reflective of your comments otherwise the message that you are trying to convey may be confusing.

8 What a research proposal looks like

A research funding application can be anything from under 50 to well over 100 pages in length and it often includes *annexes*, supporting documents, CVs, charts and letters of support.

The first page of the application form is always a summary page outlining the following:

- HRB reference code (starts with scheme abbreviation e.g. ILP for Investigator Led Projects)
- project title
- who the leading members of the research team are (lead applicant and co-applicants),
- what institute is going to manage the research funding (host institution)
- how long the project will be (duration)
- how much money they are asking for (budget total)
- a short **scientific** summary of what the researcher plans to do (**abstract**)



Application Form

Summary

Reference	
Title	
THE	
Lead Applicant	
Co-Applicants	
Host Institution	
Duration (months)	
Budget Total (€)	
Abstract	
Abstract	

The second page of the application form is a table of contents outlining the different sections contained in the proposal. Not all of these sections will be relevant for public reviewers and the sections numbers may differ depending on what scheme the proposal is for.

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- 1. Project Details
- 2. Project Description
- 3. Details of Research Team
- 4. Infrastructure and Support
- 5. Project Budget
- 6. Co-Funding Budget Commitment
- 7. Other Funding
- 8. Lead Applicant
- 9. Co-Applicants
- 10. Official Collaborators
- 11. Ethical Approval and Approvals for Use of Animals

9 Sections of the research proposal relevant to public reviewers

The <u>peer reviewers</u> will read the full application and make sure that the researchers plan to do the research to a high quality. Therefore, public reviewers are not expected to read and understand all sections of the application form. You do not need to know any details about the scientific aspects of the application.

There are specific sections of the application form that in general you **might** need to refer to when completing your review. The section numbers may differ depending on the funding scheme that the proposal comes under. However, these sections will always be within the application.

- 1. Project Details
- 2. Research Project Description
- 3. Research Team
- 4. Project Budget

Keep your focus on the questions that are asked in the review form and remember your review is important from the 'public or patient' perspective so you do not need to read and understand every part of each of these sections.

10 Where to start

If you start by reading the plain English summary (Project Lay Summary) it can give you a useful overview of the application and ideas about what to look out for elsewhere. If it does not, then it may reflect a badly written plain English summary.

Project Lay Summary

The project lay summary is similar to the project abstract in that researchers are asked to describe what they propose to do, say why they think it is important to complete this piece of work, and how they are going to go about conducting, analysing and drawing conclusions from the research.

The difference is that it needs to be written as a plain English summary such that it is clear, easy to understand, and is easily accessible to a broad lay audience. The lay summary may be used when providing information to the public with regards to the variety of research funded by the HRB and may be posted on the HRB website.

The word limit is 300 words

The project/study abstract and the lay summary should **never be identical** as the abstract is written in scientific language for a scientific audience, while the lay summary **should** be written in plain English and at a level that you would expect to find in a newspaper.

The importance of a plain English summary

A plain English summary is a clear explanation of your research.

Many reviewers use this summary to inform their review of the funding application. They include clinicians and researchers who do not have specialist knowledge of this research field as well as members of the public. If the application for funding is successful, the summary will be used on Health Research Board (HRB) and other websites.

A good quality plain English summary providing an easy to read overview of the whole study will help:

- those carrying out the review (reviewers and board and panel members) to have a better understanding of the research proposal
- inform others about the research such as members of the public, health professionals, policy makers and the media
- the research funders (e.g. HRB) to publicise the research that they fund

Plain English summary guidance for reviewers, board and panel members

- i. Does the plain English summary give a clear explanation of the research?
 - Does it help you carry out your review? If not, why not?
 - o Is the language used appropriate and clear? If not, where are these problems?
 - Are scientific terms, abbreviations and jargon explained? If not, which terms need explanation?
- ii. If this research is funded, the plain English summary will be published on a variety of websites, without the rest of this application form. Could this plain English summary be used on its own to describe the proposed research? If not, what further information is needed?

11 Finding information on public involvement in the proposal

After reading the plain English (lay) summary, you should have a good idea of what the researcher is planning to do. Now you need to find out how they plan to involve members of the public in this research. A good place to start is the project description, and in particular the section that specifically asks about Public, Patient and Carer Involvement (PPI) in the research project.

Public and Patient Involvement (PPI) in the research project

Are you including public involvement in your application? If Yes

Please **describe** all PPI at each stage of the research cycle:

- identifying and prioritising the research question
- design
- conduct
- analysis
- oversight
- dissemination

Researchers are asked to describe all PPI at each stage of the research cycle in their application.

For each stage they are asked to include the purpose of this involvement and where applicable how PPI has influenced/changed what work has been planned.

This is an opportunity for them to provide information on the individuals/groups and the ways in which they will be involved. Where members of the public/patients are involved, they should be compensated for their time and contributions; this should be reflected in the project budget.

This section should be a summary of public and patient involvement activities. Researchers are asked to go into more details in **other sections** of their application as appropriate.

The applicants can write up to 600 words in this section which is just over one page. If the researchers are not including PPI in their application, they are asked to explain why PPI is not applicable to their project.

If you do not find the information you are looking for here or you do not think that there is enough information provided in this section to answer the question, you may also need to go to the sections below. If you don't find it here, you need to include this in your feedback to the researcher.

Project Management (600 words)

Please describe how the research project will be managed.

Researchers were asked to provide details of how they plan to manage the research project to ensure that they do what they said they would do, and in the time they said they would do it. This section may tell you whether they have any plans for involving members of the public in ensuring that progress of the research stays on track.

Details of Research Team

Co-Applicant's Role

This section outlines the project roles of Co-Applicants. If there are PPI Co-Applicants their role in the project will be detailed here.

Researchers were asked that PPI contributors be named as Co-Applicants were justified by their level of involvement in the project. If there are PPI Co-Applicants in the project, it is in this section that researchers were asked to provide some information regarding their PPI Co-Applicants and their experience and expertise as relevant to the application.

Project Budget

You will need to read through this section to find out if the researcher has included any money for PPI activities in their overall budget. All PPI-related costs for the grant (except salaried personnel), should be detailed under the 'PPI costs' category in the budget. Costs may include some of the following but this will vary depending on the nature of the project:

- Compensating PPI contributors for their time (for example for time spent reviewing material/ participation in advisory groups)
- Travel expenses for PPI contributors
- Training in PPI in research

- Costs associated with PPI contributors attending conferences, workshops or training
- PPI event facilitator costs
- Room hire for PPI events/meetings.
- Hospitality for PPI events/meetings
- Companionship or childcare costs for PPI contributors while attending events, meetings, etc.

Again, we would advise you not to spend too long on this section.

Research Design and Methodological Approach

Summarise the proposed research plan, providing descriptions of individual work packages and describe how they integrate to form a coherent research application.

You may need to read through this section to find out how the researcher plans to recruit people to participate in the study.

These may be patients, carers or members of the public such as school children, older adults, or other groups with particular characteristics. This information will normally have the subtitle 'sample'; 'participants'; 'research participants' 'study subjects' or covered under a more general term such as 'design' or 'sampling'.

This is quite a technical section with lots of scientific terms that you do not need to be able to understand. We would advise you not to spend too long on this section and concentrate specifically on finding how the researchers will recruit people. This will not be applicable for all applications only those who will recruit people for their research.

Dissemination and Knowledge Exchange Plan (600 words)

Please outline the knowledge translation plan including the processes or steps that will be undertaken to support the uptake of the research findings to influence health and social care policy and/or practice.

Researchers were asked to provide details of how they plan to share the findings of their research here. This section may tell you whether they have any plans for involving members of the public in how they share the findings of their research.

12 What makes a good public review? Examples from previous reviews

Every application is different, and therefore every review will be different. This section provides some examples of public reviewer comments from previous reviews and summarises what is particularly helpful or unhelpful about them. Please note that the examples do not cover all the different sections of the review form.

- Comments about whether you think the proposed research is looking for answers that are important to patients, service users, carers or the health of the general population
- as well as why you think this.

Examples: "As a mother of children with asthma, I consider that the project reflects real issues and will test a very practical model. Attending 6 monthly reviews at a GP's can be inconvenient and time consuming. Frequently patients see different nurses or GP's - this model offers an opportunity to build up a relationship with an accessible health adviser."

"As a member of the public with a strong family history of heart attacks I believe that this research will answer an important question about whether or not a community exercise programme reduces the risk of having a heart attack"

Why are these good reviews?

- The comments are based on personal experience
- It highlights the importance of the issues
- It gives a practical view

ii. Comments about whether the researchers are measuring the right outcomes

- sometimes researchers may choose to measure changes that aren't so important to patients. For example, researchers may propose to measure the impact of a treatment on people's physical health but not whether people also experience a better quality of life. It would be helpful if you can comment on what you think is important to measure.

Example: "The reason many women seek medical help is that their day to day life has been effected by the heavy menstrual bleeding, or that it may be in the future. This study seems to be concerned about measuring the amount of blood loss and the physical effects on the women rather than the effects heavy menstrual bleeding has on the lives of the women concerned. The study would be greatly improved if it could also look at how the heavy bleeding is affecting the women's day to day living. For example, if they have to take days off work or miss social events. I feel that the research would be more useful if it also could measure the impact that heavy bleeding has on the women's lives. Including women who have this condition in the research team would help the researchers to develop the research questions so that it answers the questions that are most important to the women and also help the doctors to understand that heavy blood loss is not the only problem for these women. It would be improved vastly if they also added some impact measurements such as days off work, days/time feeling ill, impact on social and family life.

Why is this a good review?

- It describes what is important to measure from the perspective of people affected
- It clearly identifies a gap in the research application and suggests how the study could be improved

iii. Comments about whether you think the research would work in practice

- it might help to think about whether you would agree to take part in the research if it related to you and why you would say yes or no.

Example: "Interviews with bereaved carers could be an invaluable source to help understand the patient's experience, but a great deal of care will need to be taken over the timing of this discussion. If it takes place too soon after the death, the views of the carers may be significantly different to those obtained a few months later, leading to either a more positive or negative view of the patient's care. As a carer who lived in a different area to my deceased mother, how would I have been traced to participate in the research?"

Why is this a good review?

- It clearly identifies the challenges involved in working with bereaved carers
- It questions the practicality of researchers getting access to required carers
- It is based on personal experience

iv. Comments about dissemination

How do the researchers plan to publicise the findings of their work? For example, do the researchers plan to tell the people who have taken part in their study about the results? Will they be writing an article for a patient organisation newsletter or website, or are they only planning to publish an article in an academic journal?

Example: "The findings should be discussed with a group of patients to help develop recommendations for implementation (if successful) that reflect the patient experience and perspective. It might be possible to do this on an internet discussion forum on a website such as Asthma UK's."

Why is this a good review?

• It provides positive, practical suggestions for publicising results to patients, carers and service users.

v. Comments about the public and patient involvement (PPI) in the proposal

for example, have the researchers talked with any local patients' or carers' groups about their plans? If they are involving patients on steering groups, have they budgeted for their travel expenses and payment for their time?

Example 1: "The PPI is disappointing. Simply using groups to 'trawl' for information is not involvement. Prostate groups in the UK are some of the most advanced male cancer groups. The skills they have in all aspects of this study are not being utilised in the best way. Simply put, a bit of consultation and presenting groups with the already finished article is not involvement. Poorly thought out and sad to see..."

Why is this not a good review?

• While this comment highlights the lack of PPI, it does not provide suggestions on how the research team could improve the proposed PPI.

Example 2: "Having read the application it is clearly evident that the research team have fully engaged with patients and carers when developing this application. They have also entered into dialogue with patients and charities to identify important areas for discussion and utilised patients' technical skills where appropriate. Please could the research team think about the following aspects:

- Is there a specific experienced member of the research team responsible for co-ordinating, supporting and delivering patient and public involvement activities?
- Is there an age limit for patients wishing to participate?
- Will patients have the option of being able to contact their specialist nurse by phone?
- If recruitment is not as anticipated and other recruitment centres need to be sought will it be
 necessary to seek further ethical approval and would this cause a significant time delay resulting
 in the trial having to be extended?
- Would the team consider asking patients if possible to keep a brief diary (which could form part
 of the patient information sheet and be attached to the back), in order for them to be able to
 note any changes in their health or any queries that they might have while taking part..."

Why is this a good review?

- It is clear and detailed
- It highlights the strengths of PPI in the proposal
- It raises a number of questions for the research team and the panel to consider

13 Completing the review form

The review form is separated into sections. Under each section there are a number of <u>prompts</u> to help you complete the form. They are designed to help you think about assessing the funding application from a patient and public <u>perspective</u>.

Having completed your review we would ask that you now provide a rating based on the information provided in the application and the quality of the public and patient involvement in the application. Your rating (i.e. Excellent, Good, Appropriate, Fair, Poor) should reflect the comments you have made.

Excellent	You are very satisfied with the quality of the public and patient involvement in the application. PPI is evident from the early planning stages and throughout the lifetime of the award (if successful), including in decision-making at management level. Methods of involvement are innovative and maximise benefits. Planned PPI activities seem appropriately resourced in the budget. Research participant
	recruitment plans (where relevant) are well thought out and the level of commitment is clear.
Good	You are satisfied with the quality of the public and patient involvement in the application; some additional clarifications would have been

	helpful. PPI may not have started at the earliest stage of research planning OR have been included in decision-making at management level but is well embedded in the application (if successful) at stages throughout its lifetime. Methods of involvement are tailored to the research. Planned PPI activities seem appropriately resourced in the budget. Research participant recruitment plan (where relevant) are adequate and/or the level of commitment required could have been more clearly described.
Appropriate	You are reasonably satisfied with the quality of the public and patient involvement in the application. Methods of involvement are generic; some additional clarifications would have been helpful and/or PPI could potentially have been included to a greater extent from the planning phase. Planned PPI activities seem appropriately resourced in the budget. Research participant recruitment plans (where relevant) require more consideration and/or the level of commitment required is not clear.
	OR There was no public and patient involvement in the application, and you
	agree that this is appropriate due to the nature of the research.
Fair	You are satisfied with some of the public and patient involvement provided in the application. PPI could potentially have been included at other stages throughout the lifetime of the award (if successful), methods of involvement are generic and/or planned PPI activities seem to be under resourced in the budget. Research participant recruitment plans (where relevant) are unlikely to entice enough participants to take part and/or the level of commitment required is not clear. OR
	You are somewhat satisfied with the justification provided not to include public and patient involvement in the application. However, PPI could potentially have been included at some of the research stages in the application.
Poor	You are not satisfied with the public and patient involvement in the application because important information seems to be lacking. PPI does not appear to have been a significant part of the planning for the award (if successful). Planned PPI activities seem to be under resourced in the budget. Research participant recruitment plans (where relevant) are not realistic and/ or the level of commitment required is not clear.
	OR
	You are not satisfied with the justification provided to exclude public and patient involvement in the application. PPI activities could have been included in the application and resourced in the budget.

14 What happens next

After you have submitted your review, you will receive an email from us acknowledging receipt of it. We will read your review shortly after submission and may provide feedback to you on the content of your review or contact you to discuss it. The most common reasons for this are that the review:

- has a lot of sections that are left blank or only has yes or no answers
- doesn't provide an assessment of public and patient involvement (PPI)
- includes information that makes the reviewer individually identifiable
- includes comments that are potentially offensive.

If you have any questions about your review after submitting it, please don't hesitate to contact **Sara Lord** by email **ppi@hrb.ie**.

Your review will be used to provide feedback to the lead applicant of the application you are reviewing in relation to how the public and patient involvement (PPI) component of their application could be improved. Your public review will also be made available to the review panel and chair for the funding scheme. Panel reviewers will have sight of both the public review, alongside the scientific peer reviews, as well as the applicant team's response, thus it will inform the review of each application. Please ensure that you do not include any comments which you would not want to be seen by the applicants or which could identify you as the reviewer.

15 Acknowledgement

Thank you for getting involved. We very much appreciate and value the time, skills, and effort that members of the public contribute to our work. A big thank you is also due to the public contributors who helped to write this guidance.