



GUIDE TO

COSTING AND BUDGETING FOR PATIENT AND PUBLIC INVOLVEMENT IN HEALTH CARE RESEARCH



Knowledge Translation, Dissemination, and Impact

A Practical Guide for Researchers

Contents

1. What is patient and public Involvement in research?	3
2. Advice on including and costing PPI in research projects and funding applications.	4
2.1 Funding applications	4
2.2.1 The budgeting process	4
2.2 Budgeting for involvement	4
2.3 What should be included when costing and budgeting for PPI	5
2.4 Rewarding and recognising the contribution of children and young people	6
2.5 Good practice in costing and budgeting for PPI	7

1. What is patient and public involvement in research?

Definitions

When we use the term **Patient and Public Involvement (PPI)** it refers to patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public¹.

The widely used definition of **Patient and Public Involvement in research** is “*research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.*” It means working in collaboration or **partnership** with patients, carers, service users, families, people with lived experience, or the public, in planning, designing, managing, conducting, dissemination and translation of research.

involvement in research refers to research carried out ‘with’ or ‘by’ patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public. Involvement can include people getting involved in these ways:

- Setting research priorities
- Co-applicants for funding for a research project
- Members of a project steering, management, or advisory group
- Advising and developing patient information leaflets
- Co-researchers e.g. carrying out interviews with research participants
- Carrying out user led research.

Engagement is about awareness raising, sharing, disseminating knowledge about research, and engaging patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public in a conversation about research.

Participation is when people take part in a research study as participants. This might be a clinical trial, taking part in an interview or focus group or online activity. Usually it involves people consenting to take part and have their data collected so that researchers can answer a particular research question.

Community Based Participatory Research (CBPR) is a: “collaborative approach to research that equitably involves all partners in the research process and recognises the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change.” (Arbor et al 2003).



¹ The inclusion criteria may differ in other organisations, but this is intended to be inclusive of the different people served by HSE.

2. Advice on including and costing PPI in research projects and funding applications

2.1 Funding applications

When making an application for research funding, try to involve PPI contributors throughout the process and if possible, identify a budget and resources to support their involvement. PPI contributors can advise on the research topic, the question, the methodology, recruitment of participants, research tools, and plans for dissemination. They can also advise on the patient and public involvement aspects of the research at the funding application stage and throughout the project.

Having identified the stage at which PPI contributors will be part of any funded research project e.g.

- Project steering or management group
- PPI advisory group
- Co-researchers
- Data analysis
- Dissemination

it is important to cost the involvement activity and submit an itemised budget with the funding application to ensure all costs are covered. A useful starting point is to find out whether the funding agency has any guidance notes for applicants or whether they have a policy on involvement and the type of costs grant funding will cover. Involving PPI contributors in identifying the costs and resources needed may also be helpful as they will have a good idea of their needs and how long activities may take them. Working through the research cycle and mapping the timeline of the research can be helpful in identifying the PPI activity.

2.2 Budgeting for involvement

The resources needed for PPI activity will include time, funding, and personnel.

Costs may need to be amended as the project progresses and PPI activity evolves but it can be difficult to find funds if they were not built into the project plan and estimated costs at the start of the planning process and funding application.

2.2.1 The budgeting process

The following steps should be considered:

- i. Working through the project plan identify all the elements where there will be PPI activity and what those activities will comprise of. Plot these activities across the project timeline so you know exactly when the costs will arise and at what stage of the project the costs will need to be allocated.
- ii. Identify the costs for each of the activities you have listed.
- iii. Decide what form of reward and recognition you are going to use. Different forms of payment or reward include:
 - a. A payment for a one-off activity.
 - b. An honorarium paid each time a PPI contribution is made.
 - c. Payments reflecting the time, skills and activity undertaken. The payments may be on a scale depending on the activity i.e. a rate for attending a meeting; conducting interviews; speaking at an event.
 - d. Vouchers or tokens. These can be useful for one off events, or for children and young people, instead of cash payments.

- e. Fee, gift, or donation to a group such as a patient group, advocacy group, charity, or other group or network.
- f. Funding for training or learning opportunities such as a course, seminar, conference, or workshop.
- g. Honorary status such as honorary research fellow or partner which enables the contributor to access facilities such as libraries, workshops, seminars.
- iv. Find out what system your organisation has for paying PPI contributors and put the relevant processes in place before any PPI activity starts.
- v. Ensure you also identify and cost the researchers time for supporting PPI activity and individual contributors.

2.3 What should be included when costing and budgeting for PPI?

PPI activities such as:

- Membership of a steering or project management group (number of meetings taking place during the study and the number of PPI contributors attending each meeting).
- Membership of an advisory group (number of meetings taking place during the study and the number of PPI contributors attending each meeting).
- Consultation events (number of events and the number of PPI contributors attending each event).
- Providing advice on the production of patient information leaflets (number of meetings, number of hours spent reviewing documents, number of PPI contributors undertaking the review).
- Co-researcher: undertaking interviews or focus groups (number of interviews, number of PPI interviewers, number of hours each PPI contributor will spend on the activity).
- Co-researcher: research assistant working alongside the research team throughout the activity. This is likely to involve a formal contract of employment and should be costed at the institutions rate for research assistants.
- Data analysis (number of meetings, the number of PPI contributors attending, and number of hours spent reviewing and interpreting data).
- Dissemination involving co-authoring a report or an article, presenting at a workshop, seminar, or conference, producing material for sharing research through social media.

Other costs of PPI to be considered are:

- Costs associated with meetings including venues and catering for in person meetings.
- Travel expenses including the number of journeys that would be needed for each person during the project. There may also be additional costs for people who may need support when travelling.
- Subsistence including any expenses for meals or overnight accommodation whilst the contributor is in the course of the activity.
- Costs of carers for contributors who may have caring responsibilities and need a replacement carer to enable them to take part.
- Childcare costs for people who need replacement child care to enable them to get involved.
- Cost of personal assistance to enable a person with a disability who needs the support of a personal assistant to engage in PPI activity. The personal assistant may also need subsistence and travel costs.
- Remote or home working costs, including the cost of telephone calls, printing ink and paper, internet connection, licences or access to electronic meeting platforms, preparation time for meetings and remote meetings.
- Translation and interpreter services for non-English speakers.

- Training costs for PPI contributors to enable them to take part in activities. This might range from induction training to confidentiality and data protection training, to specific training to undertake interviews or focus groups. It may also involve the costs related to the time spent training.
- Fees for attendance at conferences or workshops and travel and subsistence costs (bursaries may be available).

There may also be costs associated with setting up and managing PPI activity including the following:

- Costs of equipment such as recording equipment for interviews or tablets to enable involvement.
- Recruiting PPI contributors – it is important to consider how much time the recruitment process will take and include the costs of this. It may involve working with patient organisations, advocacy groups, charities, or other bodies. Recruitment may also involve advertising the opportunities for involvement; this might be using free social media outlets or other media that might incur costs.
- Supporting PPI contributors pre and post meeting; de-briefing following interviews, focus groups, or meetings.
- Any costs associated with Garda Vetting if this is needed for involvement in the project.
- Staffing costs for any research staff who are specifically supporting PPI activity within the project or are brought in due to their expertise in PPI. The cost of administrative support for managing payments, expenses, subsistence, travel arrangements, setting up meetings or arranging interviews or focus groups.

2.4 Rewarding and recognising the contribution of children and young people

Although many of the principles remain the same as outlined in 2.1 above for adult PPI contributors, there are different issues to consider when costing and budgeting for the involvement of children and young people. It is good practice to involve the contributors in deciding how they want to be rewarded and recognised. Discussions will need to take into account the age of the children and the type of involvement they are undertaking.

Alternative options to payment may need to be considered for children and young people and they might choose to receive vouchers redeemable in shops, cinemas, or for other activities. Options such as funding other activities or learning opportunities could also be considered. Where possible, be flexible and offer age appropriate options where possible. If monetary payments are being made, take into account that not all the children may have a bank account. It is advisable to:

- Provide information for the children and parents or carers which clearly sets out the rewards that will be offered and for what activities, and how they will be given. It is important to ensure no-one is out of pocket, due to being involved, so expenses should be paid in a timely way and the process for claiming expenses should be clear.
- Be aware of any legal restrictions there might be on how many hours children and young people under 16 years can undertake paid activities.
- Ensure your organisation has a system in place that enables any reward to be administered before any PPI activity starts. Organisational policy may not allow payments to children and young people under the age of 16 years.
- Find out what the processes are for receiving rewards or payments if working with, or recruiting PPI participants through, a children's or young person's group, and how they will process them for the children or young people or group to benefit.
- Consider the costs of parents or carers, or workers from children's organisations, who are accompanying children or young people to PPI activity. They should be costed and included in the budget.

Providing recognition of their involvement and contribution in the form of certificates, letters, training portfolios, can also be a form of reward and the child or young person may use that in support of their educational or career development.

2.5 Good practice in costing and budgeting for PPI

There are some general good practice principles to consider when costing and budgeting for any type of PPI.

- i. Before recruiting PPI contributors it is important to develop a procedure for how you are going to manage reward and payments before the involvement activity starts. Check with finance and HR departments that it is accurate and can be implemented.
- ii. Where possible, pay expenses in advance or pay them promptly after the involvement activity so no-one is out of pocket as a result of their involvement.
- iii. Always provide clear information to PPI contributors about how they will be paid or rewarded and what processes they need to follow for claiming any payments or expenses. Clearly outline what can be claimed and at what rate. Ensure they know where to go for advice if they are in receipt of social welfare payments that might be affected by the receipt of payments for their involvement.
- iv. Ensure anyone who is in receipt of social welfare payments is aware of any impact receiving payments or rewards such as tokens or vouchers might have on their benefits and that they understand their responsibility to seek relevant expert guidance before accepting payments. Vouchers and tokens may be counted as 'earnings' in the same way as payments for people in receipt of social welfare.
- v. Enable the PPI participant to choose whether they wish to receive payment for their involvement activity. Not everyone may want payment, but they may want their contribution to be recognised in other ways e.g. access to training or a conference. Try to be flexible to allow for individual circumstances.
- vi. Ensure all documents are written in plain English and are available in other formats where required.

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