



RCSI Budgeting and Reimbursement Guidelines for Public Patient Involvement (PPI) in Research (Interim¹)

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¹ These guidelines are considered ‘interim’ as the National PPI Ignite Network is working collaboratively with all seven University PPI Ignite sites to develop a standardised set of PPI Financial Reimbursement Guidelines. These are expected to issue in 2022, and these RCSI Guidelines may be updated accordingly.

1. Contextual Background – What is Public Patient Involvement (PPI)?

Patient and Public involvement (PPI) seeks to involve patients, patient advocates, carers and/or stakeholders as advisors and collaborators at various stages during, or if feasible throughout, the health research process. Patient and Public involvement (PPI) is increasingly recognised by research bodies, funders and the literature as an important approach to improve the quality, relevance, ethical conduct, dissemination and implementation of health research in Ireland.

The Health Research Board (HRB) defines ‘public’ as *‘everyone in Ireland who has an interest in health and social care as a public service including potential users of services’*, defines patient as *‘people who use services such as patients, service users, clients or their carers’* and defines “involvement” as the *‘active involvement between people who use services, carers, the general public and researchers.’* (HRB Strategy 2021-2025: Making An Impact).

‘PPI Contributor’ is the preferred term for people from the patient and public population who give their time and expertise to contribute to a research study. PPI Contributors may be people who are users of medicines, medical devices and healthcare services, or who have, or care for someone who has, a specific health condition, or who have a specific interest or insight into the health research topic under investigation.

It is important to note that PPI does not include the use of people as ‘participants’ in research (also known as research ‘subjects’) and does not include gathering their data for use in research projects. The Patient Contributor role as a research advisor is fundamentally different from a ‘research subject’ or ‘research participant’. The latter may consent for their data to be used in research but are not involved in the research process i.e. planning the research question(s), research design, research funding, research recruitment, research conduct, analysis, write up or research dissemination.

There is great value in embedding a PPI approach in research projects. The growing literature evidences that a PPI approach can aid researchers to identify relevant research questions, design research studies, collaboratively secure funding, improve the accessibility of research information/materials, discover unique insights in pre-clinical research, improve patient participation and retention in research studies including clinical trials, engage in data gathering and data analysis, as well as enhance the effective communication of research findings to patient/public populations and policy makers (Brett 2012; 2014; Crocker 2013; Shippee 2015; Price 2017).

There are also reciprocal benefits to Patient and Public Contributors in terms of enhanced confidence, greater understanding of scientific/healthcare research topic and a sense of contributing to overall patient population health (Minogue 2005; Kara 2013; Brett 2014).

2. Why have these guidelines been developed for PPI in Research in RCSI?

RCSI is strongly committed to facilitating researchers to engage in high-quality, respectful and ethical PPI from generation of ideas to implementation of evidence in healthcare. RCSI has recently been awarded HRB National PPI Ignite Network funding as one of the seven Lead University Sites to progress PPI in Ireland.

Systematic reviews have identified that among the most commonly cited challenges by researchers to engaging in PPI are the logistics of time and funding required to engage in effective PPI and the desire to avoid tokenistic or even exploitative PPI.

By considering, and where feasible, implementing these guidelines developed by the RCSI PPI in Research Committee, researchers acknowledge and value the time, skills and unique expertise that patient and public contributors bring to the research process. This approach affirms our core mission: *“Placing the patient at the centre of all that we do, our values of Respect, Collaboration, Scholarship and Innovation continue to unite and direct our purpose.”* (RCSI Strategy 2018-2022)

3. When should researchers consider and discuss reimbursement for PPI?

Reimbursement should always be discussed with PPI Contributors in advance of any contributions. PPI can take place at different points or throughout the life cycle of a research project and so the researcher / research team should consider clear and equitable criteria for PPI reimbursement at project design stage. It may also be necessary to consider reimbursement if PPI Contributors are required as a research project evolves.

Researchers should follow the guidance provided by the funder/organisation in relation to PPI, budget and resources, across both the application stage, and management of the grant should it be funded. Where funding schemes permit, researchers should factor in costs to reimburse PPI Contributor expenses and include a payment in respect of the PPI Contributors' time, skills and expertise.

In some research projects, there may not be available budget for PPI activities. PPI can also take place without reimbursement, but having an early conversation about PPI will ensure that everyone is clear about the role of PPI and the objectives for both researcher and PPI partners.

There may also be alternative ways to acknowledge the PPI Contribution in non-monetary ways e.g. sharing authorship on a paper, a conference presentation, training, public acknowledgement etc. so it is important to discuss that what may be meaningful acknowledgement with each individual PPI Contributor.

Finally, if the research project is planning to involve a patient organisation in PPI in ways that will significantly impact on the patient organisation's staff time and resources, it may be appropriate for researchers to discuss if a percentage of the grant allocation may be required to cover this involvement, and to request that at grant application stage.

4. Recommended Process for Budgeting for PPI in Research

Step 1 – Clarify the PPI approach in your research

- Consider and clarify the expected function of PPI at each research stage e.g. research design, pre application, and pending a successful grant application outcome, at planning, implementation and dissemination stage.
- Consider and clarify the role of PPI Contributors and how PPI Contributors may be included in the research process across the various stages
- Clarify how PPI will be evaluated in the research. Use existing PPI guidance, frameworks and advice for this.
- Plan the research involvement activities listing what PPI activities will be completed at each of the research process from development through to dissemination.

Step 2 - Identify the costs associated with the PPI activity on the research project.

Take into consideration:

- **Costs associated with PPI activities** such as a meetings, consultations (room hire, catering, facilitation), recruitment of PPI contributor (advertisements, communication), provision of training (technical, research), staffing, and evaluation of PPI.
- **Out of pocket expenses** which PPI contributors will incur due to their involvement in the research project. For example, travel, accommodation, subsistence, childcare, replacement carer, communication costs.
- **Payments to PPI contributors** in recognition of their time, skills and expertise.

Step 3 - Develop the PPI Research Project budget

- An online calculator is available on the National Institute for Health Research (NIHR) Involve website: <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>.
- This calculator is in pound sterling (£), so euro conversion rates will apply (£1 = approx. €1.14, check xe.com for up-to-date rate).
- The online calculator is a guiding tool, and researchers should verify the costs associated with their PPI plan.

Step 4 - Processing of payments and how to prepare

- Refer to the institutional PPI payment policy/guidelines, as well as to the grant guidelines if applicable.
- Discuss and clarify what budget is available and how will payments and expenses be made
- Involve PPI contributors in this process from budget development and payment agreement including expenses, compensation and payment details
- Clarify if the PPI contributor is a PAYE worker, self-employed, in receipt of social welfare payments, or unemployed but available for work. Ensure that the PPI participant consider the impact of payments on their social welfare benefits, other payments or taxation. For further information see https://www.citizensinformation.ie/en/money_and_tax/tax/capital_taxes/capital_acquisitions_tax.html
- Consider developing a written agreement with PPI contributors as to their role in the project, the expected time investment required, and how/when they will be reimbursed for this.

5. Guidelines for Reimbursing PPI in Research

Reimbursing expenses associated with engaging in PPI activities is a recognition of the PPI contributor's time and their important role in the research project. It is generally expected that the cost to PPI contributors associated with involvement are covered by the research grant e.g., bus/train fares, mileage, parking charges, accommodation and subsistence (if appropriate). Depending on the topic of the research and research population researchers may also need to factor in childcare or carer costs.

The following are reimbursement options for PPI expenses and time and should be discussed by the researcher and PPI participant before work commences, to agree which option fits best. Please note that if time reimbursement is paid via RCSI payroll (see options below), it will be subject to tax. Please ensure that PPI Contributors are aware of this.

- 5.1) Time** – This may include but is not limited to PPI Contributors' time on PPI panels; on advisory/steering committees; reviewing research documentation; conducting research interviews or focus groups; delivering research presentations/training; travelling to meetings/research sites. Based on consultations with other PPI IGNITE centres in Ireland, as well as guidance from the National Institute of Health Research (NIHR) and INVOLVE UK guidance, the following rates are suggested for PPI activities:
- PPI Half day rate €85
 - PPI Full day rate €170
 - PPI Brief activity €30 (e.g. involvement in a brief task or activity requiring little or no preparation such as participating in a short online meeting or reviewing a brief document)

All reimbursement costs for time offered are honorarium payments as form of reward and recognition offered for the contribution patient, carer and public contributors make to research at RCSI. This payment does not mean that PPI contributors have a contract of employment with RCSI,

PPI contributors are not obliged to accept reimbursement for their time if they would prefer not to receive it, or they may request to be offered a lower or higher amount due to individual circumstances, which is at the researcher's discretion to discuss and pending budget availability.

- 5.2) Travel** - This may include public transport, road tolls, fuel costs, parking costs etc necessary for the PPI Contributor(s) to be involved in the research process. Note that receipts must be kept with a log of travel related to the research project (e.g. dates, cost incurred, purpose of travel etc.)
- 5.3) Accommodation** - In the case where accommodation is required, the INVOLVE guidance rates could be used for grant budgeting: Reimbursement for 3-star accommodation are: €140 per person per night including breakfast and VAT in Dublin, €90 per person per night including breakfast and VAT elsewhere. Receipts must be kept. If PPI Contributors choose to stay with a relative or friend, RCSI are not able to offer to cover any of these costs.

- 5.4) **Subsistence** – In the case where meals or refreshments are required while attending or travelling to PPI in research activities, either receipts for reasonable, itemised subsistence should be reimbursed or a pre-agreed daily subsistence rate factored into the budget. Please note costs for alcoholic drinks are not eligible for subsistence reimbursement.
- 5.5) **Childcare Expenses** - If the PPI Contributor has childcare responsibilities, the research team may need to reimburse the cost of providing necessary alternative care whilst they are away at PPI in research activities. This will need to be discussed and any arrangements agreed in advance. The PPI Contributor will need to provide evidence of the costs, such as an invoice or receipt from their childcare provider.
- 5.6) **Care Expenses** - If it is necessary for an informal (unpaid) carer (such as a relative or friend) to accompany the PPI Contributor, the carer's expenses (travel, accommodation and meals / refreshments) should also be covered. Also if the PPI Contributor has care responsibilities, (for example for a disabled person or an elderly person with support needs), the research team may need to reimburse the cost of providing necessary alternative care whilst they are away at PPI in research activities.
- 5.7) **Communication Costs:** It may be necessary for the PPI Contributor to have access to mobile credit, a mobile device, internet access or a secure IT device, depending on their role in the research project.

6. Recommended Reimbursement Options for PPI Contributors

- 6.1) **Vouchers** – The researcher could use vouchers, e.g. one4all or other voucher when discussed with PPI participant. Researchers and PPI participants should note that €500 is the maximum amount that can be paid per PPI Contributor per annum through RCSI as gift vouchers. Researchers should process the payment for vouchers using AGRESSO, including the relevant budget codes. Please see: <https://staff.rcsi.ie/administration-and-support/finance/agresso>
- 6.2) **Payroll** – The researcher can use payroll to request payment for work done, and must provide everything else that casual payroll requires such as justification of why the PPI contributor is being paid. The assumption is that the payee has a bank account and they must have an Irish PPS number (see Appendix 4 for details on how to apply for a PPS number).

Please note that payroll payments are subject to tax. If the PPI Contributor is a PAYE worker, this is factored into their tax obligation. If they are self-employed, they can declare it as income in their yearly return.

The researcher should complete the payroll identity form for payroll processing and a bank details form with the PPI contributor. Forms should reach the salaries office by the 5th day of the month for payroll processing. The form can be found on the RCSI webpage as follows <https://staff.rcsi.ie/administration-and-support/finance/payroll-services/payroll-forms> Enquiries can be sent to payroll@rcsi.ie . The relevant budget codes should be included (See Appendix 3).

Please note if PPI Contributors are relying on certain social welfare payments, accepting payment for PPI work or even doing this work voluntarily may affect their social welfare payments. Please ensure they check this with their Social Welfare Officer or via https://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/voluntary_work_and_social_welfare_payments.html

- 6.3) **Invoicing** - PPI contributors who are registered for VAT may invoice the researcher for their time to be paid through Accounts Payable.

Also, PPI contributors who are Sole Traders and have a company registered can supply the company registration number to Accounts Payable for payments to be processed.

While grants normally cover VAT costs (e.g. SFI, HRB, EU etc), there may be some grants that do not cover VAT so the researcher should check the Funding agency guidelines in relation to reimbursement of costs which are associated with a VAT charge.

If the funder or allocated grant budget does not cover this cost, the researcher should consider how they will cover this cost.

Appendix 1: References cited in these Guidelines

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Appendix 2 Sample PPI budget

This is a sample of typical Public Patient Involvement related costs for researchers to consider. However each project is different so please ensure to discuss potential PPI costs with your research team and PPI contributors.

Cost	Year 1	Year 2	Notes / justification
PPI Recruitment	€0	NA	PPI contributors will be recruited through existing patient organisations with no charge for this.
Steering committee meetings	€510	€510	3 PPI contributors attending steering committee meetings every 6 months. Meetings will last 2 hours and require 1 hour prep. €85 per meeting.
Training costs	€340	€0	PPI contributors will also have half a day of training introducing them to the project and project specific information. One PPI contributor will 2 hours training on qualitative data analysis. €85 per person.
Travel costs	€100	€120	Travel for meetings and training. €XX per person depending on distance to travel, per meeting, training day or event.
Project specific activities	€185		Project specific activities, e.g. reviewing transcripts and papers, study document. €185 for a full day of activity.
Conference co-presenting		€340	Fees for attendance and presentation by 2 contributors at a local conference (€170 per person per day)
Co-presenting at a public event		€255	Fees for attending and presenting at a half day public event. €85 per person x3 .
TOTAL	€1135	€1225	€2360

Appendix 3 Sample Payroll Identity form



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PAYROLL IDENTITY DOCUMENT FORM

Due to Revenue Commissioner Guidelines issued for Republic of Ireland residents, it is necessary to attach documentary evidence of your PPS number with this questionnaire.

This may consist of one of the following items:

- Certificate of Tax Credits in respect of a previous employment
- P45 form from a previous employment that clearly shows the PPS number in respect of an earlier year of assessment or from a former employer in respect of the current year of assessment
- Social Welfare Services Cared or PPS Registration Letter issued by the Department of Social Protection
- P60 issued by an employer clearly showing the PPS number
- P21 Balancing Statement issued by the Revenue Commissioners or any other correspondence from the tax office specifically quoting the PPS number and name
- Payslip from a previous employer clearly showing the PPS number

PLEASE USE BLOCK CAPITALS

Name: _____

Home Address: _____

E-Mail Address: _____

Phone Number: _____

PPS Number: _____ Date of Birth: _____

Name of Bank: _____

Bank Address: _____

Bank Sort Code: _____ Bank Account No: _____

IBAN Code: _____

BIC Code: _____

Please note we are unable to process incomplete or illegible details.

Office Use Only:

Appendix 4: How to apply for an Irish PPS number

Personal Public Service Number (PPSN)

Your PPSN is a unique reference number that is needed for all dealings with public service agencies, including Revenue.

With effect from 1 January 2021, applying by email is no longer possible, and it has been replaced by an online PPS Number application service via MyWelfare.ie.

In order to apply for a PPS Number via the online service, individuals will need to have a basic MyGovID account. This can be set up at www.mygovid.ie. Applicants will need to provide evidence of why they require a PPS Number, and they will need to upload photos or scanned copies of the following:

- an identity document
- a proof of address, and
- evidence of why the individual need a PPS Number.

If an individual is applying for a PPS Number to take up employment, they must have a signed offer of employment from their employer confirming when their position is to start or when it started. The employer's letter should be on company headed paper and with the employer's contact details together with the employer/company registered number.

Further information regarding the PPSN application process can be found here. [gov.ie](http://www.gov.ie) - [Get a Personal Public Service \(PPS\) Number \(www.gov.ie\)](http://www.gov.ie)

You can also use the Online Enquiry Form to contact Client Identity Services or telephone (071) 967 2616, Lo Call: 1890 927 999. If calling from outside the Republic of Ireland please call +353 71 967 2616 to have the necessary forms sent to you in the post

Notification of PPS Number

Following successful registration, customers will be advised of their new number through the issue of a letter of notification sent automatically to the address given on the application form within 3 to 5 working days. This letter is acceptable proof of one's number for transactions with specified bodies for public services e.g. health, education, Revenue, employment, Driving License.

Appendix 5: Acknowledgments and Citation of these Guidelines

Acknowledgements: Version 1 of these guidelines was collaboratively drafted by members of the PPI in Research Committee in April 2021, led by Professor Frances Horgan, Professor Gianpiero Cavalleri (Chair) and Dr Fiona Manning. The guidelines were edited by Lorna Kerin, RCSI PPI in Research Manager, 20th May 2021. The guidelines were reviewed and approved by RCSI Finance Office and by RCSI Senior Management Team on 6th July 2021.

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