Rewards, Payment and Recognition for Patients, Carers and Public Members (PCP) Involved in Research

For the National Institute for Health Research (NIHR) Imperial Patient Safety Translational Research Centre (PSTRC)

Key contact
Anna Lawrence-Jones - a.lawrence-jones@imperial.ac.uk or 020 7594 3149

Checklist

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Have you read the below document?</td>
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<tr>
<td>Have you filled out the non-pay roll fee form including signing it?</td>
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<tr>
<td>Have you kept receipts from your travel (as proof of travel) and attached them to your expense claim form?</td>
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<tr>
<td>Have you returned the expense claim form and receipts to the office either in person or by post to: Anna Lawrence-Jones, NIHR Imperial Patient Safety Translational Research Centre, Imperial College London, Medical School Building, St Mary’s Campus, Norfolk Place, London, W2 1PG or by email and scanning to <a href="mailto:a.lawrence-jones@imperial.ac.uk">a.lawrence-jones@imperial.ac.uk</a></td>
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1. Introduction

Patients, carers and public members (PCP) who are involved in research should be rewarded and their contribution should be recognised. Therefore, payment should normally be offered (INVOLVE, 2013 & 2014). Some PCP members may not wish to receive financial reward and this should be acknowledged. Other incentives should be also available for those who do not want to receive financial reward or for those whose benefits may be affected. Expenses i.e. travel, subsistence, childcare costs should be also reimbursed.

1.1 Why rewards, payment and recognition are important for patients / public

Payment, rewards, incentives and reimbursing expenses are important, because they:

- are ways of accessing additional expertise from people who have used services
- are tangible ways of rewarding people for the contribution they made
- go some way to equalising potential power disparities
- support social inclusion and help promote socially valued roles
- can help clarify mutual expectations of involvement for staff and for patients / public.

1.2 Principles for involvement

It is important to make clear from the outset the arrangements and how much payment, what incentives or expenses are being reimbursed and when they should be expected. This helps inform individual’s choices about whether to become involved. INVOLVE (2014) further recommends to:

- strongly consider the offer of payment as part of any reward and recognition policy
- consult with the public members about how they would like to be rewarded for their contributions

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Based on the policy for PP involvement at the NIHR Biomedical Research Centre: http://www.imperial.ac.uk/media/imperial-college/medicine/sph/PPIRewards.pdf
• members of the public should not be financially worse off when involved in research - all reasonable expenses should be covered, as a minimum requirement.

2. Payment
2.1 Payment
The payment will depend on many factors, i.e. one-off/ongoing involvement, level of involvement: attending meetings, preparation, strategic/governance, skills, expertise, experience, but also funding available. It is important to plan, i.e. research centre strategy / initial funding proposal, and make clear from the outset the rate and arrangements for payment. It may be helpful to ask the following questions when deciding the payment.

• What level of skills, expertise and experience are you seeking / expecting from patients/public?
• What are the time commitments involved in the role they are playing in the project (i.e. preparation, reading, travel, communication, meetings and so on)?
• What level of responsibility do you expect the person to hold in the project? (INVOLVE, 2013)

If the relationship and the payment is ongoing / regular, we could use either:
  a) an honorarium or agreement per year or per project for the involvement, or
  b) a contract with payment based on the hours / days that the PCP spends on the project.

The honorarium/agreement requires a commitment from both researchers and members of the public to deliver. Both parties should set up clearly the involvement of the PCP member, at what level and what activities. It may mention approximate time/days required, but it is more flexible regarding time spent than a contract payment based on hours/days.

If the contract is based on the hours/days spent on the project, different levels of payment are suggested and presented at Table 1.

2.2 One-off payments
‘One-off’ payments may be provided for less regular involvement or limited input from members of the public.

2.3 Vouchers
Proxy payments such as vouchers can be offered as a reward and recognition for involvement. Vouchers for retail outlets may be provided instead of cash payments for children, young people and other members of the public providing limited input.

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2 One-off payments and vouchers are now treated the same as any other payment or earnings from the Department for Work and Pensions. For those on welfare benefits, these payments are subject to the same restrictions as payments for longer involvement. It is the responsibility of the individual member of the public to declare these payments. From April 2014 ‘notional earnings’ rules for people on benefits carrying out involvement work in research were abolished. ‘Notional earnings’ are where people are regarded as having received payment even if they actually refuse the payment being offered for any reason. This change should make administrative payments for involvement work much easier (INVOLVE, 2014). The changes on notional earnings apply to all benefits from April 2015.

3 As above
Table 1. Patient and Public Involvement in Research - Rates of Payment

<table>
<thead>
<tr>
<th>Nature of input</th>
<th>Rate per hour</th>
<th>Rate per day/meeting (not proportionate to the rate per hour)</th>
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<tbody>
<tr>
<td><strong>User-controlled</strong> research:</td>
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<tr>
<td>• PCP member leads on research projects</td>
<td>£50 or more</td>
<td>£200-£250</td>
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<tr>
<td>• PCP member leads on design &amp; methodological choices</td>
<td></td>
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<tr>
<td>• PCP member has individual responsibility for interviewing or working on analysis of research data preparation.</td>
<td>£50</td>
<td>£200</td>
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<tr>
<td>• PCP member peer reviews research proposals and funding applications</td>
<td>£30</td>
<td>£120</td>
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<tr>
<td><strong>Collaboration</strong> with patients/members of the public:</td>
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<tr>
<td>• PCP member is involved in writing research / grant applications</td>
<td>£30</td>
<td>£120</td>
</tr>
<tr>
<td>• PCP member is involved in designing research tools, i.e. participant information sheets, questionnaires</td>
<td>£30</td>
<td>£120</td>
</tr>
<tr>
<td>• PCP member co-facilitates research sessions where some minimal preparation is required</td>
<td>£30</td>
<td>£120</td>
</tr>
<tr>
<td>• PCP member collaborates with researchers to design, undertake and/or disseminate the results of research</td>
<td>£30</td>
<td>£120</td>
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<tr>
<td><strong>Meetings and Consultations</strong></td>
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<td></td>
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<tr>
<td>• PCP member prepares for and attends individual meetings / teleconferences</td>
<td>£10-£20</td>
<td>£70 (£20 minimum per session)</td>
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<tr>
<td>• PCP member is part of a group attending meetings, i.e. steering group committee meetings for a research project, patient advisory group</td>
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<tr>
<td><strong>Training and Conferences</strong></td>
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<tr>
<td>• PCP member attends relevant external training course / conference / event</td>
<td>No fee is normally payable. Costs of training/conference/event, travel, subsistence, accommodation and other expenses are reimbursed/agreed in advance.</td>
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3. Expenses

3.1 Travel expenses

Travel expenses will be reimbursed by the finance department of Imperial College London through an expense claim form. The costs usually covered are included at Table 2.

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4 From April 2014 reimbursed expenses to people on benefits carrying out paid involvement work in research are ignored. As people who are in receipt of benefits have strict limits on earnings the previous rule was difficult for administration. The changes on reimbursed expenses apply to all benefits from April 2015 (INVOLVE 2014).
Table 2. Involvement in Research - Travel Expenses

<table>
<thead>
<tr>
<th>Mode of Travel</th>
<th>Type of receipt needed for reimbursement</th>
</tr>
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<tbody>
<tr>
<td>Standard class rail</td>
<td>Original receipt/travel ticket or photocopy if ticket needed for return journey. First class tickets will not be reimbursed, even if this option is cheaper.</td>
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<tr>
<td>Underground, overground and bus</td>
<td>Original receipt/travel ticket or photocopy if ticket needed for return journey. If oyster card used, the maximum travel expense for the zones used should be reimbursed.</td>
</tr>
<tr>
<td>Mileage</td>
<td>Usually 40-45p per mile up to 10,000 miles per financial year. Parking fees off Trust/College property will be reimbursed if required to attend an event relevant to the research involved with. Agree before travel.</td>
</tr>
<tr>
<td>Taxi</td>
<td>Reimbursed or paid using firms contracted to Imperial Trust/College. Other taxi travel will be reimbursed where no other means of travel can be reasonably used and on presentation of original valid receipts. Agree before travel.</td>
</tr>
</tbody>
</table>

3. From April 2014 reimbursed expenses to people on benefits carrying out paid involvement work in research are ignored. As people who are in receipt of benefits have strict limits on earnings the previous rule was difficult for administration. The changes on reimbursed expenses apply to all benefits from April 2015 (INVOLVE 2014).

3.2 Subsistence
Subsistence costs for time spent away from home and the costs that need to be met because of this, i.e. paying for meals, snacks and refreshments. Agree before involvement. The Centre has to right to decide what are reasonable subsistence costs, on a case by case basis.

3.3 Other expenses and costs
Other expenses or costs may be required for involvement in research. These may be discussed and agreed in advance with the PPIE Manager. People may have their own arrangements in place and charges will vary; otherwise the costs below may need to be organised through an agency.

- Childcare
- Carer costs
- Personal assistants

Other expenses or costs may be required, such as below.

- Interpreters and other support needs: Costs for interpreters, signers or other support the PCP member requires for their involvement will be also paid / reimbursed.
- Overnight accommodation: PCP members travelling some distance or taking part in an involvement activity such as training or attending a conference over several days, may need overnight accommodation.
- Home office costs: Telephone calls, postage or printing. If this is likely, it is important to decide how to reimburse these costs.

4. Other forms of reward and recognition
Other rewards, incentives or recognition may be offered to PCP members.

- PPI / PE training opportunities such as ‘Training the Trainer’, assertiveness training, understanding and basics of research and clinical trials, training in research methods.
• **Attendance at conferences and relevant events** (and the opportunity to present) such as INVOLVE, Involve to Evolve conferences.

• **Funding for other training or continuous development opportunities**, internal or external, such as IT, presentation skills, and communication skills.

• **Fee, donation or gift to a group or network** instead of payment to the individual. This gives the group or network control over how they use the money for their own interests.

• **Advice and support on personal and professional development**, such as help with CVs, job applications, etc.

• Giving people an **honorary status of Imperial College**, as a lay fellow or research partner is often used as a way to reward and recognise their contributions. This will also facilitate their access to College email, libraries, seminar series and other research opportunities.

• **Acknowledgment** of the PCP member contribution as co-author to the research in reports, publications, posters and presentations.

• **Providing feedback** to PCP members on the research development, process and outputs.

5. **Timeline of payment**

Once a correct expense form and receipts are received, the Centre can take **up to 6 weeks** to reimburse your costs, due to internal processes. Please contact us if this is problem or if you have not received your payment within this timeframe.

6. **Working with other organisations/Other guides**

It is acknowledged that PCP members who work with the NIHR Imperial PSTRC may also work with other partner, local or national organisations. In addition, there are other guides for rewards, payments and incentives available: Imperial College Health Partners (ICHP) Patient and Public Participation Payment Principles (2015), NIHR Clinical Research Network (CRN) Mental Health Model Payment Policy (2014).

It should be made clear from the outset of involvement which guidelines are followed and what arrangements are made for specific projects and individual PPI member (see 1.2).

**References**


