UNIVERSITY OF OXFORD

Guide for researchers working with Patient and Public Involvement (PPI) representatives

UNIVERSITY OF OXFORD
NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

NHS
National Institute for Health Research

This document has been put together primarily to support researchers in the University of Oxford's Nuffield Department of Primary Care Health Sciences and those funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford at Oxford Health NHS Foundation Trust.

However, any researcher at the University of Oxford working with PPI representatives is welcome to use this resource to guide them.

Thank you to all the researchers and PPI representatives who gave their time to help develop this resource.

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Section 7 – Finances

Please refer to Section 2 for information about budgeting for PPI work in your funding application.

A few things that you could usefully do to help your PPI representative include;

- Having plenty of expense claim forms available at meetings. You could also prefill them in with some details including 'n/a' in the employee number box and your own contact details where it asks for claimant address details.
- Ask them their bank details at the start of their involvement and keep a record of this on their file to assist with any payment or reimbursement issues that might arise.
- Be sensitive in handing out claim forms and talking to people about Benefits. Some people may be embarrassed if they are making a claim when others do not – nobody should be made to feel awkward about this. Assume that everyone may be on Benefits and do not make assumptions about this based on how they dress or speak!
- You should always be clear with people that they do not have to accept either expenses or payment but that there is no shame in doing either.
- Some people might ask you to donate their expenses or payment to a charity of their choice but because the University of Oxford is a charity we are unable to make a direct transfer payment. It would of course be entirely up to the recipient what they choose to do with any monies they receive from us.
- In principle payment relates to children & young people as much as it does to adults. However, it is good practice to get permission from parents or guardians before giving payment to a minor. Where a young person or child is involved and it is their parents who have incurred expenses to enable their involvement, then it is the parents who should make the claim for their expenses to be reimbursed.

This whole section will have to be reviewed once the payment policy is agreed.

7:1 Reimbursement of PPI representative expenses

Reimbursement for expenses are not taxable.

The University of Oxford expense form can be found here;
expenses form

It is strongly recommended that you encourage any PPI representative in receipt of State Benefits to contact this helpline (7.3) to ensure that there are no adverse effects of their involvement work with you, prior to their involvement.

Where you are paying expenses you should be clear with the PPI representative right from the start that they must get your permission before claiming expenses not listed in their agreement with you. You should pay expenses as follows;

- Mileage for private vehicles at 45p per mile for the first 10,000 business miles in the tax year and then 25p for each business mile over 10,000 in the tax year.

- Cost of public transport
- Taxi in cases which can be justified e.g. multiple people travelling to same place, personal safety, disability or efficiency.
- Cost of a paid carer providing the PPI representative's caring role in their absence. This to include travel/accommodation/subsistence requirements and hourly costs.
- Cost of a paid carer supporting the PPI representative to attend the meeting due to their own support needs. This to include travel/accommodation/subsistence requirements and hourly costs.
- Standing allowance of £5 per meeting to cover the cost of telephone calls, paper, printing ink and home office sundries, should they be used.

You should encourage your PPI representative to make their expenses claims as soon as possible and arrange the payment to be made as soon as possible after they do so. Anything that is more than 12 months old will not be paid. Evidence of expenses in the form of a receipt or ticket must be provided. Where receipts are difficult to obtain (for example the use of Oyster cards or calls made on mobile phones) copies of bills or computer printouts with the relevant section highlighted can be accepted.
Whether your project is part of the work of the Nuffield Department of Primary Health Care Sciences or the Oxford NIHR CLAHRC Oxford you should send your claim forms to the budget holder or delegated authority for authorisation and they will then send it on to the finance team.

It is good practice to pay people on Benefits (at least) their expenses on the day and for this reason you may prefer to arrange for petty cash. (You would do this across the board so as not to embarrass any individuals)
To do this at the Nuffield Department of Primary Health Care Sciences:

a) Ask the Finance Officer for a float from petty cash up to a limit of £50 for a meeting and each claim can only be a maximum of £20
b) If you will need more than £50 per event then give the Finance Officer a week's notice of needing a bigger float. The maximum for any one claim will remain at £20
c) You could reimburse the PPI representative out of your own pocket and then use their receipts to make your own expense claim to the department.

The use of petty cash <u>only</u> applies to expenses, not payment for time.

NIHR CLAHRC Oxford researchers who work for departments other than that of Primary Health Care Sciences should consult their own Finance Officer for their own department's advice on raising petty cash.

Please note that if a PPI representative asks for payment by cheque they should be warned that this may delay payment – BACS transfer is the University's preferred method.

7:2 Payment of PPI representative

This refers to payment for time which is over and above the reimbursement of expenses
Payment for time is taxable and should be declared for tax purposes.

You can use the expense form to cover this element too. The University of Oxford expense form can be found;
expenses form

It is strongly recommended that you encourage any PPI representative in receipt of State Benefits to contact this helpline (7.3) to ensure that there are no adverse effects of their involvement work with you, prior to their involvement.

You will have made clear to the PPI representative from the advertisement onwards what, if any, payment is available. This will be based on what you budgeted for when you made your funding application.

You may use the INVOLVE recommended rates which are;

- Full day meetings: £150 - to include all prep and follow-up
- Half day meetings: £75 – to include all prep and follow-up

- Short pieces of work which require little prep or follow-up, such as a telephone meeting or reviewing short documents; approx 1-2 hours: £20.00
- Work totalling approx 2-3 hours, including shorter face to face meetings: £50
- Longer pieces of work such as reviewing/commenting on strategic documents/policies or plans, via email or post. Approx rates for this are:
    - Reviewing short documents, as above: £20
    - Reviewing for example mid-length reports (~50-100 pages): £150
    - Reviewing large reports/documents, (over 200 pages): £200

Payments made for time to PPI representatives are deemed by HMRC as income. This applies even if payment is made via vouchers. PPI representatives receiving any payments or incentives should be made aware that this may impact on their entitlement to Benefits. Breach of benefit conditions can result in an individual's Benefits being stopped. It is the person's responsibility to keep to the conditions of those Benefits on what they can do and amount they can be paid. (7.3)

PPI representatives are also responsible for their own related pension contributions, National Insurance (NI) and income tax.

Once you have appointed the PPI representative you can get their bank details and then complete a Payment Request Form.

In some cases you may decide that you would rather pay the person with vouchers. Nuffield Department of Primary Health Care Sciences uses the Gifts for All company for this. You will need to raise a purchase order and wait for them to be paid before they will send you the vouchers so you would need to allow at least a month for this process. Alternatively you can request Blackwell's vouchers from the Finance Officer and they will be available within 3 working days. NIHR CLAHRC Oxford funded researchers who work outside the Nuffield Primary Care Health Sciences should consult their own Finance Officer for their own department's advice on paying with vouchers.

In either reimbursing or paying, the PPI representative may ask you to make a direct payment for the item such as direct payment to their carer. In such circumstances speak to the PPI Coordinator who will help.

Please note that if a PPI representative asks for payment by cheque they should be warned that this may delay payment – BACS transfer is the University's preferred method.

7.3 Benefits Advice Service for involvement

There are two confidential free services providing advice and support;

It is strongly recommended that you encourage any PPI representative in receipt of State Benefits to contact the appropriate helpline to ensure that there are no adverse effects of their involvement work with you, prior to their involvement. It will help them if you tell them where the funding for your project comes from.

INVOLVE (Jan 15 for one year pilot) which will offer personal advice and support on how payment of fees and expenses for public involvement might affect people in receipt of state Benefits.

It is available to:

- members of the public involved with NIHR organisations
- members of the public involved in studies funded by the NIHR
- staff within NIHR organisations who are supporting members of the public to get involved

The process is:

- contact INVOLVE on benefits@invo.org.uk or 02380 651088, stating which part of the NIHR you work in (for example, BRU, NIHR CLAHRC Oxford, LCRN)
- members of the public can contact INVOLVE using the contact details above (INVOLVE staff do not need to know anything about their Benefits situation)

- the person enquiring will then be given an email address (or telephone number) to contact the Benefits advice service directly, together with a unique code that will need to be quoted.
- E-mail is preferred for the first contact. The service will then arrange a time to call.

It is important to allow members of the public with enquiries to contact the Benefits advice service directly, rather than raising any enquiries on their behalf. This will avoid misinterpretation or confusion in any advice offered.

If you are not sure whether your project qualifies to use this service, please contact INVOLVE on Benefits@invo.org.uk or 02380 651088.

N.B The service is not able to give advice on tax or National Insurance enquiries, or on Benefit queries relating to payment for participating in research (for example, for taking part as a subject of a clinical trial or research study).

NHS England has also arranged for a helpline to be available to patients and staff who have queries about being involved with NHS England's work. Bedford Citizens Advice Bureau provides a telephone helpline service to help resolve any benefit concerns that arise from payment of fees and expenses for public involvement. The service should be contacted via email involve@bedfordcab.org.uk with a brief summary of the query, or by calling 01234 330604.

One of the biggest difficulties for people on benefits because of ill health or disability is that Jobcentre Plus offices can interpret involvement as readiness for work whether or not payment is being offered. NHS England has developed a standard letter which explains clearly that involvement opportunities with NHS England are not an indication of readiness to work, or employment. Suggest that the CAB is asked for this where appropriate.

Section 8 – Training

The principle behind offering training is to enable the PPI representative to contribute as fully as possible. They should all be given the basic induction and introductory reading material (see section 6). In addition, it may be necessary to arrange specific training for a given project as need arises. This cannot be prescriptive because of the nature of the research (some will be more technical than others) and because the starting knowledge of PPI representatives will vary.

8:1 PPI representative training

Currently there is no specific in-house training provided for PPI representatives. The Coordinator does intend to arrange some training however and this document will be updated when this is available.
Topics might include;

What is evidence?	Clinical audit or research?
Ethics	Bias
Quantitative/ qualitative research	Study design
Phase I – IV trials	Systematic reviews
The research cycle	Research terminology
Informed consent	What is good research?
Critical appraisal	Communication
Influencing in meetings	Dealing with conflicts
Chairing meetings	

It may be possible to offer your PPI representative national training from INVOLVE or regional training by partner agencies. The Coordinator will be able to advise if any is available.

8.2 Training in best practice in PPI for researchers

Currently there is no specific in-house training provided for researchers in how to work well with PPI representatives. The Coordinator does intend to arrange some training however and this document will be updated when this is available.
Topics might include;

Why do PPI?	PPI in the research cycle – maximum impact
Changing culture	Tackling barriers
Involvement in different research areas / activities	Chairing meetings
Acknowledging and using lay skills	Where can you get support?
Influencing in meetings	Dealing with conflicts

Section 9 - Running meetings that involve PPI representatives

Remember that it is vitally important to acknowledge your PPI representatives input and encourage their involvement. Say thank you to them at the end of the meeting. Send a follow up email that thanks them for their input. Make sure that PPI representatives input is minuted. Phone the person before and after their first meeting to help put them at ease and see if they have any questions about the agenda. Ideally contact them like this before all meetings.

It is considered good practice to always have at least two PPI representatives in any meeting. This enables them to gain confidence from each other and for the meeting to get more than one view.

9.1 Terms of Reference

Whether you are managing your PPI input through focus groups or including representatives on trial steering committees or other groups you will have to consider how the group functions. It will be good practice for the group to agree its own Terms of Reference at the beginning of their work and to review these occasionally.

See Appendix for template Terms of Reference

9.2 Good practice in running a meeting

Things to consider when setting up a meeting that includes PPI representatives

- ✓ Make sure that the room you are using is accessible that there are disabled toilets that can be accessed by someone in a wheelchair and that there is a hearing loop.
- ✓ Make sure that there is disabled parking and that other parking is as easy as possible. In a place like Oxford if parking is not possible then ensure that you consider holding the meeting out of town where people can park or ensure that you choose a venue on easy bus routes.
- ✓ Provide not just the address of the venue but a map and any other details necessary to make it easy to find for someone coming for the first time. Provide the phone number for the reception in case of last minute difficulties.
- ✓ Think about how people are going to enter the building – will they need to be met, given a parking permit or directed to the actual room?
- ✓ Ask people if they have any special dietary needs (e.g. vegetarian, gluten free etc.) and be sensitive to the patient population you could be meeting with e.g. people with diabetes.
- ✓ Provide up-to-date travel expenses and payment forms and ensure they are filled out correctly – be aware that some people may be embarrassed to claim if others are not and alter your system appropriately (providing in a sealed envelope etc.)
- ✓ Don’t make the meetings too long and plan breaks (particularly relevant if your PPI representatives have a disability or condition that means they need the toilet more

often or they cannot sit in a chair for too long…) Breaks will generally be welcomed by all!

- ✓ Consider evening or weekend meetings if you need to attract working age and young adult participants
- ✓ Consider your venue if you want to attract a particular cohort. For example holding a group in a Sure Start Centre with facilities for play may attract young parents.
- ✓ Have an agenda for your meeting that you share at least a week before the meeting
- ✓ Create an atmosphere where people feel able to share ideas by always welcoming input from all, encouraging people to speak up and thanking those who make suggestions.
- ✓ Give plenty of notice of meetings – do not assume that because your PPI representative is retired for example that they do not have many other commitments

Before the meeting, facilitators should

- ➢ Try to ensure that they are working in pairs as meetings can often be busy and it is hard to welcome people, deal with the room and refreshments as well as taking a leading role or taking minutes
- ➢ Try to provide basic refreshments such as tea and coffee on arrival, and allow time for this in the agenda. If the meeting is longer consider whether it is appropriate to provide a light meal or another drinks break and make arrangements for this. If you are doing this you will need to find out about any special dietary requirements of attendees beforehand. When thinking about your venue remember to book an accessible room: Are there disabled toilets on the same floor? Lifts? Is there a hearing loop?
- ➢ Think about how you are going to fully involve those with a disability or condition but how you are going to do this respectfully without drawing unnecessary attention to them.
- ➢ Think about what you want to get out of the meeting but also what the attendees could get out of it.
- ➢ Make sure that you think about how you are going to gather feedback about the meeting.
- ➢ Offer PPI representatives the opportunity for a chat to answer any questions they have individually and check that they are happy

On the day facilitators should

- ❖ Ensure the room is comfortable, warm and not too noisy and that the seating allows attendees to see and interact with each other
- ❖ Bring with you enough copies of any paperwork sent to the attendees; do not assume that they have been able to print them out at home. (You should establish with new PPI reps if they have a printer at home and if using it is acceptable to them)
- ❖ Greet each attendee and start the session with introductions. It’s a good idea to get each person to introduce themselves and say a little bit about why they came; this

helps break the ice and makes people more confident about contributing later on. Name badges may help for those with poorer memories or who did not hear a name. You may find that name plaques stood in front of the person if the meeting is round a table are helpful if distances make name badges hard to read.

- Remember basic housekeeping; make people aware of fire alarms and exits, toilet location etc.
- Remind people of the purpose of the meeting, run through the agenda and mention the beginning and ending times, and whether there will be any breaks.
- Outline the ground rules of the session. Is it ok for people to ask questions at any time? Remind people not to talk over one another. Ask people to respect each other's contributions. Make a clear statement about the confidentiality of the information provided by participants. Explain how the information from the meeting will be used. Ask people to respect each other's confidentiality too.
- Ask if there are any questions before you start.
- Make sure that everyone has the chance to speak – you might need to actively encourage quieter members to do so and discourage some from dominating proceedings
- Try to avoid becoming defensive if there is criticism or problems are raised as this will stifle further conversations about these issues.
- Avoid letting the meeting run overtime; people may need to get back for caring responsibilities etc.
- Ensure people are clear about what will happen next; will there be another meeting? Will there be further correspondence? What are the next steps for the project?
- Ensure people have filled out their expense forms and know what to expect from the reimbursement procedure, such as how long it can take.
- Thank the group for their time.
- Provide an opportunity for feedback – verbal, written etc. Consider how you are going to make this open – does it need to be anonymous for example? How real can that be in a small group? Do not assume that everyone can read or write.
- Give people the opportunity to confirm that they are happy that their contribution is being accurately recorded.

After the meeting

Write to people and thank them for participating. Summarise what happened and let them know what will happen next. Invite people to give you feedback.

9.3 Helping People to Contribute Effectively During Meetings

There are many reasons for non-participation during meetings including lack of preparation, shyness, being overawed by rank or someone's specialist knowledge or being put off by another's aggressiveness or dominant behaviour.

To draw out the silent type and protect them from intimidation it might be helpful to ask questions that tap their expertise, praise their good ideas, openly note their contributions, and call on those that are shy or junior first.

Of course you may also have to limit the long winded. This can be done by setting the ground rules at the start including how long any one person can speak for at a time. You should also request that remarks be confined to the topic of discussion. If someone still insists on an opera length speech you may have to tactfully but firmly insist that you move on.

It is equally important to remain focused on the agenda and what needs to be achieved. To do this you will want to summarise progress and remind everyone of the meeting's objectives. You will also have to interrupt if the discussion gets out of hand, off topic, too heated or rowdy. Act quickly if a serious disagreement arises.

Sometimes a participant may have something worthy to contribute but may not be the best public speaker. At such times it is the chair's job to rescue that person by helpfully summating what they think he/she was trying to say.

You should work to encourage diverse points of view, especially if it is a problem solving or brainstorming session. Well run meetings enable a group of people to achieve more than the sum of their individual efforts, through the creation of synergy and the combination of their collective expertise.

You should encourage all opinions and perspectives to be explored but be prepared to highlight bias and oversights. Some participants will need to broaden their viewpoints while others must be encouraged to be more realistic.

To generate ideas you may want to try brainstorming, asking open questions (ones that cannot be simply answered by yes or no), encourage partial ideas, reserve your own ideas until the end, clarify and paraphrase for others (make sure you ask them to confirm that you have it right), and the use of verbal and non-verbal reinforcement

You may wish to offer a de/briefing meeting for PPI representatives before and/or after the meeting.

Section 10 – Working with the seldom heard

10.1 Working with children & young people

Rather than repeat a range of good practice here, please refer to other expert publications in this area.

If you have any specific queries or would like further help please speak to your PPI team.

http://www.invo.org.uk/find-out-more/involving-children-and-young-people/

http://www.nihr.ac.uk/get-involved/young-people-and-research.htm

http://www.ncb.org.uk/what-we-do/research/involving-children-and-young-people-in-research

http://www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people

http://nuffieldbioethics.org/project/children-research/

10.2 Reaching adult seldom heard groups

Seldom heard' is a term used to describe groups who may experience barriers to accessing services or are under-represented in healthcare decision making.
Traditionally, some of the groups identified include;

- rural communities,
- black & minority ethnic (BME) groups,
- gypsies and travellers,
- lesbian, gay, bisexual & transgender,
- asylum seekers and refugees
- prisoners
- homeless
- young carers.

However, in reality, teenagers, employees, people with mental health issues or a learning disability or substance misuse issues and many others may be considered as seldom heard, due to the fact engagement may not be straightforward.
The only way to actually engage with different groups is to understand them individually and tailor involvement to them accordingly.

- **Understand their needs and priorities** – this will help to define the way you engage
- **Find out how they like to get involved** – align your approach with this
- **Determine the way they prefer to be communicated with and what tools they use** – tailor your method, for example, to social media, video, or even workers in the community
- **Find out who they trust and have good relationships with** – develop a relationship with those stakeholders and ask them to help you reach people

- **Don't expect everyone to feedback in the same way** – from online snap surveys to face-to-face discussions, adjusting the approach to get the right results is important

Professor Louise Locock of Oxford University has done some specific work in this area; http://www.invo.org.uk/posttypeconference/patient-involvement-as-a-route-to-seldom-heard-groups/

Oxfordshire County Council has been proactive in both training their staff in this area and recruiting PPI representatives from traditionally seldom heard groups. Contact with them can be made via your PPI team.

Some specific advice is available from the Social Care Institute for Excellence;

http://www.scie.org.uk/publications/positionpapers/pp10.asp

If you have any specific queries or would like further help please speak to your PPI team.

Section 11 – Ongoing support

11:1 PPI representative ongoing support

You should arrange to provide the following support as a minimum;

- Meeting papers to be sent 1 – 2 weeks in advance
- Phone contact before and after meetings to answer queries
- Access to additional information provided on PPI by INVOLVE as needed
- Help with claiming expenses and payment
- The template logbook form for them to record their expenses received etc.
- Ongoing training informally provided in house to help explain aspects of the project
- The offer of additional formal training as it becomes available
- Regular feedback so that they know what progress is being made on the project. Wherever possible include feedback on how their impact has made a difference to the work.
- Providing their contact details to the PPI Coordinator so that they will be included in any relevant support such as the PPI newsletter.

Many people choose to become involved with research for the opportunity to learn new skills, make a contribution, and meet new people. Consideration should be given to other forms of support and recognition to enhance the experience for individuals who get involved. This might include, for example, training and learning, attending conferences, confidence building, help with ongoing learning, CV development and future employment. If you do not feel able to provide this please talk to the PPI Coordinator to discuss possibilities.

Remember that even if you are paying people for their time it is important to thank them for their contribution regularly. An occasional formal letter of appreciation from the head of the research project will also be much appreciated.