



# Welcome to PenPIG

**The patient and public involvement group for the National Institute  
for Health Research Collaboration for Leadership in Applied Health  
Research and Care for the South West Peninsula  
(PenCLAHRC)**

Draft Version January 2017



# **Welcome to PenPIG**

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## **What is PenPIG and PenCLAHRC?**

PenPIG is the Public Involvement Group for the NIHR CLAHRC for the South West Peninsula (PenCLAHRC).

NIHR stands for the National Institute for Health Research. This organisations' mission is to manage Department of Health funding to improve research for the NHS and social care. One of the ways the NIHR does this is to fund collaborations between universities and the NHS through organisations called CLAHRCs (Collaboration for Leadership in Applied Health Research and Care).

The CLAHRCs are regionally based organisations covering most of England. PenCLAHRC works across Devon, Cornwall, and Somerset to make sure health research in these areas addresses the real needs of patients and practitioners, and is used to improve healthcare.

### **About PenPIG**

The purpose of PenPIG is to advise PenCLAHRC on Patient and Public Involvement (PPI) and to act as a 'critical friend'.

PenPIG is a friendly and informal group of about 15 volunteers with a range of experiences as patients, carers and supporters. PenPIG members are often active in their communities. The group includes men and women of different ages, cultural backgrounds and experiences of health services. What they share is a commitment to work with clinical and academic professionals to help healthcare research become more relevant and accessible to people who access services.

As well as attending quarterly PenPIG meetings members contribute to individual research projects and PenCLAHRC management board meetings.

Examples of things that members of the PenPIG do are:

- Advising researchers about what changes could make a difference for patients and service users.
- Helping to identify and prioritise research questions about things that are important for patients, their families and carers.
- Commenting on research proposals from a 'common sense' perspective.
- Thinking about how to make research projects more attractive and useful to the people who might take part in them.
- Reviewing questionnaires, information sheets and research summaries to make sure they are clear and understandable.
- Attending PenCLAHRC management board meetings on behalf of PenPIG.
- Telling other people about the work done by PenPIG and PenCLAHRC.

The PenCLAHRC PPI Team supports PenPIG through:

- Supporting the administration of PenPIG
- Providing and signposting training opportunities to support PenPIG members gain confidence and skills needed for their role.

## **Membership**

Membership is flexible reflecting the differing circumstances and availability of PenPIG members. There is no requirement for members to take part in all the projects or activities of PenPIG. If for any reason attending meetings or commenting on documents becomes difficult, a member can take 'time out' by informing the involvement team or the membership secretary.

Members will be offered an informal "one to one" meeting with a member of the PPI team annually. This will be a chance to review their involvement activities and to identify any support needs.

In order to make sure the group remains viable, members who have not taken 'time out' and who do not respond to emails or letters will be assumed to have left the group after missing two consecutive quarterly meetings.

Each member of PenPIG is required to read and sign the PenPIG Terms of Reference which is a more formal description of the purpose and structure of PenPIG.

### **As a PenPIG member you can:**

- Decline to undertake any task or take part in any activity for whatever reason, without having to offer any explanation.
- Step down at any time, with no disadvantage to you whatsoever.

### **What you can expect from PenCLAHRC:**

- PenCLAHRC will only hold personal information with your permission, which is necessary for keeping in contact and supporting you to undertake the role of a PenPIG member.
- This information will remain confidential, safeguarded and managed in accordance with best practice
- You will be entitled to claim for travel and other agreed out of pocket expenses.
- You will be offered training and support to undertake any of the tasks asked of you as a PenPIG member.
- You will receive feedback on how your involvement has influenced the work of PenCLAHRC.

### **What PenCLAHRC expects from you:**

- To abide by the PenPIG code of conduct and treat other PenPIG members and staff with respect and courtesy.
- Play an active and constructive role in discussions.
- Treat information shared by PenPIG members and projects discussed by researchers as confidential. That means it cannot be shared or attributed afterwards, unless the person concerned has given their express permission for this.
- Give apologies if you are unable to attend a meeting.
- To make use of the PenPIG complaints procedure, should there be any dispute.
- Inform the PPI Team if you wish to step down.

If you feel you have been unfairly treated by another member of the group or by someone in PenCLAHRC please tell them or bring this to the attention of the PPI team. These issues will be dealt with in line with our complaints procedure.

### **Training**

You do not need any special training to become a member of PenPIG. However, as a member you will have the opportunity to develop your knowledge and skills by attending training workshops that you may find useful. Training provided by the PPI team is free of charge.

There may also be opportunities to attend training provided by other organisations. These organisations may charge. PenPIG will not normally cover these costs unless the training is essential for a particular project that you are involved in on our behalf.

Group members who feel that they need specific training or support in order to play a full part in group activities should discuss this with the PPI team.

### **Recruitment of PenPIG members**

Sometimes people contact us and ask if they can join PenPIG and sometimes existing members suggest we invite someone who could contribute experiences and ideas that would be helpful.

When someone wants to join they will be asked to provide a short statement of why they would like to join the group and any experience they have as patients, carers, supporters or in community activities. This statement will be circulated to the group by the membership secretary. The group will discuss (usually by email) whether this statement offers something that will help the group to advise and support research in PenCLAHRC more effectively from a patient and public point of view.

The membership secretary will be responsible for advising the applicant of the decision of the group and, if accepted, providing the new member with all appropriate information and paperwork.

### **Formal roles within PenPIG**

PenPIG has two voluntary secretaries:

- The business secretary who is responsible for providing administrative support to PenPIG, working with the PPI Coordinator.
- The membership secretary who acts as the first point of contact for new members. You can find out more about these roles under PenPIG Secretary Roles.

Members take turns to chair meetings, although not everyone chooses to do this.

## **Payments**

We try to ensure that members are not out of pocket for participating in research. When attending PenPIG meetings or undertaking activities for us you will be able to claim for reasonable expenses in line with the policies of the University of Exeter. Members are able to claim the cost of travel, including mileage, in line with university policies. Subsistence (meals, hotels and other expenses such as childcare) may be claimed but will need approval by the PPI team for each instance.

When you attend meetings and contribute to research projects, we also offer a participant payment as a recognition of your involvement. To claim this you will need to fill in a form requesting payment and giving your bank details. It will be paid directly into your bank account by the university.

Detailed information regarding travel reimbursement, participant payment claims, receipts, and financial procedures can be found in the next section, PenPIG Payment Policy.

## **Additional opportunities**

Members of PenPIG will also be able to attend free seminars that are organised or advertised through PenCLAHRC. These are not a part of normal PenPIG activity. Attendance is voluntary and a matter of personal interest. For these activities neither a participant payment nor travel expenses will normally be paid.

PenCLAHRC also sometimes organises conferences and 'learning together' events. Attendance at these events will not normally attract a 'thank you' payment unless the group member is presenting at the conference. However, reasonable out of pocket expenses can be claimed.

Group members will also sometimes have opportunities to attend conferences and seminars in other institutions. Again a participant payment will only be paid if the group member is presenting at the event on behalf of PenPIG. However expenses and fees may be claimed if there has been a prior agreement that the group member is attending as a representative of PenPIG.

Group members with particular access and support needs should discuss these with the PPI team in advance of any event they wish to attend.

## **Tax and Benefits**

Involvement is voluntary and is not a job. The PPI team can provide you with a letter describing your voluntary role and confirming that we do not require you to attend meetings or undertake work for us.

It is the responsibility of individual PenPIG members to ensure that they comply with tax and benefit regulations.

INVOLVE offers free personalised advice to people involved in NHS and NIHR research and who claim benefits. As a member of PenPIG, you are eligible for this service.

<http://www.invo.org.uk/resource-centre/benefits-advice-service/>

You can email them at: [benefits@invo.org.uk](mailto:benefits@invo.org.uk) or phone 02380 651088.

For advice about tax you can contact the HMRC help line

<https://www.gov.uk/government/organisations/hm-revenue-customs/contact/income-tax-enquiries-for-individuals-pensioners-and-employees>

Telephone: 0300 200 3300

The Citizens' Advice can also advise you on benefits and tax issues.

<https://www.citizensadvice.org.uk/>

## PenPIG Payments Policy

We try to ensure that members are not out of pocket by participating in research. When attending PenPIG meetings or undertaking activities for us you will be able to claim for reasonable expenses in line with the policies of the University of Exeter. This document is intended to give a guide to those payments. If you incur any expenses not covered here please feel free to discuss this with a member of the involvement team.

### Travel

#### Car Journeys

For the first 100 miles of any journey 45p per mile, thereafter 25p per mile.

We encourage car sharing. If you car share we will reimburse the driver an extra 7p per mile, including the picking up distance.

#### Motorcycle Journeys

For the first 100 miles of any journey: 24p per mile, thereafter 9p per mile.

#### Bicycle journeys

For all journeys: 20p per mile

Mileage should be claimed by the most direct route. No receipt is needed to claim journeys, but a receipt is required if you also claim parking costs. Claims for other travel costs will need proof of purchase, for instance train/bus tickets or taxi receipts.

Travel expenses can normally be paid back to you in cash on the day of the meeting. You will be asked to complete a form and attach any receipts.

### Subsistence

Claims for subsistence, including hotel stays, should always be agreed by the involvement team in advance of travel for each meeting.

Reimbursement for breakfast is only available if you are required to leave home before 7.30am

Reimbursement for an Evening meal is only available only if you are required to arrive home after 8.30 pm. Receipts must be provided for all subsistence claims.

#### Subsistence Rates

Breakfast:	£9.00
Lunch:	£9.00
Evening meal:	£20.00
Bed & Breakfast/hotel:	£85 (except London)
Bed & Breakfast/hotel:	£227 (London)

### Childcare

Childcare should always be agreed by the involvement team in advance. It can only be reimbursed if you can provide a receipt from a registered childcare provider. Receipts must



be dated for the day of the meeting only. If you're unsure, please contact the team before the meeting.

### Enablers

Enablers for someone who has an official 'personal budget' and who use enablers to participate in meetings can only be reimbursed if you provide a receipt from a registered provider.

### Participant payments

PenPIG members are also offered a small sum in recognition of their contribution. These are paid directly into your bank account. You will be invited to complete a claim form and fill in your bank details.

Participant payments for PenCLAHRC-based work are calculated on the basis of:

<b>Participant payments</b>	<b>Pre-meeting preparation</b>	<b>Attendance</b>	<b>Post-meeting liaison</b>
For a half day meeting (up to 3.5 hours)	£10	£10	£5
For a full day meeting (4 hours or more)	£20	£20	£10
For commenting on a lay summary of approximately one page	£10 for completing a set of questions about the summary and emailing these to the PPI team		

This means that a half day meeting (3.5 hours or less) will normally attract a participant payment of £25. A full day's meeting (more than 4 hours) will normally attract a participant payment of £50.

Participant payments may be offered for other activities, like reviewing documents or commenting on questionnaires by email. The involvement team will indicate if payment is offered in the invitation. Members may wish to keep track of the amount of time the task took to report back to the involvement team.

No participant payments are normally offered for attendance at lectures and conferences (unless presenting), or for attending training.

## Payments Summary

Activity	Participant payment	Travel/subsistence	Fees
PenPIG meeting	Offered	Reimbursed	Free
Internal PenPIG training, including shadowing roles	Not offered	Reimbursed	Free
Attending PenCLAHRC board meeting or the final prioritization meeting (including shadowing)	Offered	Reimbursed	Free
PenPIG Business Secretary and Membership Secretary hand-over meeting	Offered	Reimbursed	Free
PenCLAHRC seminars	Not offered	Not normally reimbursed	Free
External Training	Not offered	Not normally reimbursed	Not normally paid
PenCLAHRC conferences	Only offered if presenting on behalf of PenPIG	Reimbursed	Costs paid by PenCLAHRC
External conference	Only offered if presenting on behalf of PenPIG	Only reimbursed if representing PenPIG	Only paid if representing PenPIG

### Keeping track

You are advised to keep a note of your claims for your reference.

The involvement team aim to send participation payment forms to the University of Exeter Finance team on the third Thursday of the month. These payments will usually arrive in your bank account 2-6 weeks after submission. If after 6 weeks you are still unpaid, please contact the involvement administrator.

To help you manage payments, we aim to provide monthly statements for each PenPIG member. This is usually sent by email on the last Thursday of the month. It lists all claims submitted including: the date and title of meetings attended, the amount claimed per meeting, the date sent to finance, and the lump sum you should receive in your bank account.

## **PenPIG Code of Conduct**

### **General**

- Members will not bring PenPIG or PenCLAHRC into disrepute
- Members will not speak or write on behalf of the group without the prior agreement of the group.
- Any correspondence sent on behalf of the group will be made available to all members of the group.
- Members will work within the rules laid down in the Terms of Reference.
- Members will observe collective responsibility for group decisions.
- Members will respect others and not make insulting or disparaging remarks. This includes any discriminatory behaviour or comments on the grounds of age, disability, gender reassignment, race (including ethnic or national origin, colour and nationality), religion or belief (including lack of belief), sex and sexual orientation.

### **Conduct at meetings**

- Members will follow the guidance of the Chair in the conduct of the meeting.
- Members will be courteous to each other at all times and allow each other to speak.
- Mobile phones should normally be switched off or to silent. If it is necessary for a member to keep their phone on they should inform the meeting of this and leave the room to answer any calls.
- Members will remember that the purpose of the meeting is to benefit the community, not specific individuals.

### **Conflicts of Interest**

- Members will disclose any interest, whether personal or on behalf of any group they represent, that they consider may affect or influence their approach to any matter under discussion.

### **Confidentiality**

- Members will respect the confidentiality of other group members and that of any research project that is brought to the group for consideration. Information shared in confidence will not be discussed outside the group without prior agreement from all those concerned.

### **Breach of the Code of Conduct**

- Will be dealt with informally where possible, in accordance with the complaints procedure.

PenPIG members will observe this Code of Conduct whenever they:

- Are acting in their role as a PenPIG member.
- Are representing PenPIG or PenCLAHRC.

## **Patient and Public Involvement Complaints Procedure**

We know that things don't always go the way we all hope they will. Sometimes we might say the wrong thing or do something that upsets a member of the group. It is useful to have a clear way to deal with this if it happens. These procedures are to help us sort out these kinds of problems.

### **Principles**

- We always want to hear if someone is unhappy with something within PenCLAHRC.
- Where possible complaints will be resolved by the agreement of the people involved.
- We will acknowledge receipt of all complaints and will try to resolve them within 28 days of the complaint being received.

### **Informal Resolution**

If you have been offended by someone's behaviour it is best to try and talk to that person directly if you can. They could be a service user, carer, patient, an employee of PenCLAHRC or a partner organisation. If you do not feel confident about talking to someone who has offended or upset you, you may ask a member of the involvement team to speak to them, informally, on your behalf.

### **Formal Procedure**

If you do not feel able to do this, or have tried talking to them and are still dissatisfied, you should complain in writing to the involvement team. Your complaint should clearly explain what it is that has concerned or upset you and, if possible, what you would like us to do about it. This will help us to resolve the problem.

A member of the involvement team will try to contact all the people involved in the complaint, within seven working days of receiving your complaint. They will try find out each person's point of view. They may also ask for copies of any written documents that would help them understand what has happened.

If your complaint is about an employee of PenCLAHRC or one of its partner organisations the involvement team will inform the appropriate Human Resources Department. They will try, if possible, to resolve the problem at this stage.

If your complaint is about a member of the involvement team you may write to directly another member of the team, to the PenCLAHRC PPI lead or to XXX (external to the PPI team). They too will try to resolve the problem at this stage.

If resolution is still not possible or if the issues raised are very serious they will be addressed by the PenCLAHRC PPI lead or XXX in consultation with the involvement team and PenCLAHRC management.

A decision will then be made as to what further action, including mediation if appropriate, is required. The decision will be communicated to everyone involved.

**Independent Appeal**

If the people involved in the complaint are still not happy with the outcome, they will have the option of calling on our independent external adjudicator. Currently our independent external adjudicator is YYY, a previous member of INVOLVE staff and independent PPI Consultant. She will review the complaint and how it has been processed. She will then recommend any further actions that need to be taken by PenCLAHRC.

## PenPIG Secretary Role Descriptions

### Membership Secretary

**Purpose of Role:** To support the recruitment and welcoming of new members of PenPIG.

**Tasks:**

In collaboration with the PPI team...

- to act as first point of contact for potential new members and to obtain a personal statement from them for circulation to PenPIG.
- to facilitate PenPIG members' discussion of membership applications and to inform the applicant of the outcome.
- to ensure that new members of PenPIG are introduced to the group, receive a copy of the Welcome Pack and sign the Terms of Reference, which will then be passed to the appropriate PenCLAHRC staff member for safe keeping.
- to liaise with the involvement team to organise an "induction" meeting with new members as necessary.
- to ensure new members are added to the mailing list.
- to support any PenPIG member considering becoming a future membership secretary and provide appropriate "handover" to successor in the role.
- to liaise with the business secretary and members of the PPI team.

**Tenure:** This position will normally be held for a period of 12 months.

**Reimbursement:** This role is voluntary but an **additional** participation payment of £25 per half day may be claimed for the preparation and running of induction meetings as agreed in advance with the PPI team.

### Business Secretary

**Purpose of this role:** To provide administrative support to PenPIG and support the PPI team in sharing information between PenCLAHRC and PenPIG.

**Tasks:**

In collaboration with the PPI team...

- to ensure that all PenPIG members are given the opportunity to chair a quarterly meeting and to support and assist the Chair in conducting the meeting.
- to ensure that all PenPIG members are informed of the date, time and venue of quarterly meetings.
- to circulate a draft agenda (prepared with the PPI team) and invite PenPIG members to suggest additional agenda items.

- to draft the minutes of the quarterly meetings, and once approved by the PPI team to circulate them to members of PenPIG. Ideally this should happen within two weeks of the quarterly meeting.
- to support any PenPIG member considering becoming a future business secretary and providing appropriate “handover” to successor in the role.
- to liaise with the membership secretary.
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**Tenure:** This position will normally be held for a period of 12 months.

**Reimbursement:** This role is voluntary but an **additional** participant payment of £25 may be claimed for each quarterly meeting attended and minuted to reflect the additional work involved. Payments for additional work must be agreed with the PPI team in advance.

## PenPIG Terms of Reference

The purpose of PenPIG is to advise PenCLAHRC about patient and public involvement (PPI) in health and social care research and to act as a 'critical friend'. It is a voluntary role.

PenPIG activities may include:

- Identifying issues of concern to patients and service users.
- Prioritising research questions.
- Commenting on research proposals and protocols.
- Advising on recruitment strategies and research participant wellbeing.
- Reviewing research documents and questionnaires for clarity.
- Attending and contributing to PenCLAHRC management board meetings.
- Telling other people about the work done by PenPIG and PenCLAHRC.

PenPIG members can:

- Refuse to undertake any tasks or take part in any activity without offering any explanation.
- Step down at any time, with no disadvantage to themselves.

PenCLAHRC will:

- Provide a named person as primary point of contact.
- Only hold the personal information about PenPIG members necessary to support them.
- Safeguard and managed that personal information in accordance with best practice
- Offer training and support to undertake the tasks asked of PenPIG members.
- Provide feedback on how involvement influences the work of PenCLAHRC.

Membership of the group will be:

- Members of the public who have an interest in health research.
- As far as possible, members will include a diverse group in terms of gender, age, cultural background and experience of using primary and secondary health services.
- Normally, 15 people will serve in the group at any time.

Business meetings will be held approximately once every three months (quarterly).

- At the close of the quarterly meeting the chair will ask for a volunteer to chair the next.
- Each member will be given the opportunity to chair a quarterly meeting, but there will be no obligation to do so.
- In advance of the meeting the chair and the PenPIG business secretary, will contact all members of the group to invite subjects for inclusion on the agenda.
- The PenPIG business secretary will be responsible for ensuring that papers for the meeting are sent to members at least one week prior to the meeting.
- Minutes of quarterly meetings will be recorded by the PenPIG business secretary and circulated to the group, normally within two weeks following the meeting.
- Members should let the business secretary know as soon as possible if they see



- any errors or would like any amendments made to the minutes.
- Amendments should also be mentioned at the next quarterly meeting, for clarity.

Members who do not send apologies or respond to emails/ letters will be assumed to have left the group after missing two consecutive quarterly meetings, unless they have notified the involvement team or the membership secretary that they are taking 'time out'.

Sub-groups will be formed to work on specific projects or issues. These may be time limited and intended to deal with a specific task, or they may deal with on-going issues.

Members of the group will be able to claim reasonable out of pocket expenses for PenPIG meetings or meetings where they represent the group. Individuals who have particular expenses because of support and access needs should discuss these with the involvement team.

In addition, normally a participant payment will be offered in recognition of contributions made to quarterly business meetings, sub-group meetings and meetings where members represent the group. This will be set at a prudent and reasonable amount.

Current rates for reimbursements and participant payments will be available on the PenCLAHRC website or from the involvement team, on request.

Members of the group will have the opportunity to develop their knowledge, and skills. Details of training opportunities will be provided by the involvement team. Attending training will not normally attract a 'thank-you' payment though out of pocket expenses may be reimbursed.

Individual membership and support needs will be reviewed annually.

PenPIG can only work if we create an environment of mutual respect and trust. The PenPIG code of conduct has been agreed to support this. The PenPIG complaints procedure is the mechanism we have agreed to use if there is any breach of the code of conduct or if we feel we have been treated unfairly by an employee of PenCLAHRC or one of its partner organisations.

By signing this document you also agree to abide by the code of conduct and the complaints procedure.

**Agreement to Abide by these Terms of Reference**

By signing these terms of reference I agree to abide by the rules as laid down in them.

**Signed:** ..... **Date:** .....

**Please print your name:** .....



## Contacts

PenCLAHRC Patient and Public Involvement Team  
University of Exeter Medical School  
South Cloisters  
St. Luke's Campus  
Exeter EX1 2LU

PPI team email: [piexeter@exeter.ac.uk](mailto:piexeter@exeter.ac.uk)  
Team mobile( for meetings): 07785 724813