PATIENT AND PUBLIC INVOLVEMENT (PPI) IN RESEARCH HANDBOOK

A handbook to support your planning and preparation for carrying out PPI activities in your research
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Background and Purpose

In July 2015, the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East of England (CLAHRC EoE) delivered a Patient and Public Involvement (PPI) in Research Masterclass for researchers, in each of it’s 3 main locations (Cambridgeshire, Hertfordshire and Norfolk). This was designed by a steering group comprising lay members, researcher representatives from each of CLAHRC’s six research themes and chaired by a member of the core team. The format and content of the Masterclass was informed by a researcher survey on the respondents’ experience of PPI in research, their needs for support, and preferences for training provision. Case-study presentations from both PPI representatives and researchers were used to support an introduction level of training, in which attendees could learn about PPI in an engaging way, through the shared experiences.

In addition to providing training, the steering group planned to produce a handbook for researchers on carrying out PPI activities. A smaller working group of CLAHRC researchers was established to create this handbook. At each Masterclass, the researchers attending provided feedback and ideas for the handbook, which has been used to inform the content and format.

The aim of the handbook is to be a ‘first-port-of-call’ resource for researchers new to PPI and / or at the start of their project. It is to support researchers in planning and carrying PPI activities throughout the various stages of their research.

It is designed for researchers and includes:

- Key points to consider when planning and carrying out PPI in Research
- Existing online resources and tools for signposting
- Both PPI representative and researcher perspectives, gathered from the masterclass, steering group and working group.

What is Involvement in research?

INVOLVE (the national coordinating centre for patient and public involvement) defines ‘involvement’ as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This might include involving people in setting research priorities, design, carrying out the research, analysis, reporting and dissemination, rather than participating in research or in research education.

The research cycle on page 4 provides examples of involvement at each stage of the research process from idea to implementation.

How is Involvement different to Engagement and Participation?

Engagement is about raising awareness of research, sharing knowledge and creating a dialogue with patients and the public. For example, this could be public events showcasing research activity and ways that people can get involved.

Participation is when patients and members of the public are recruited to take part in a study. This typically entails consenting people to take part and collecting data from/about them to help answer a research question.

INVOLVE definitions of Involvement, Engagement and Participation
http://www.invo.org.uk/public-involvementparticipationengagement-in-research/
THE RESEARCH CYCLE
Ways that Patient & Public Involvement (PPI) Representatives can be Involved

- Inform research priorities
- Initiate research ideas
- Collaborate to identify topics for research

- Affirm importance of research question
- Clarify the research question
- Inform &/or co-design the study protocol
- Ensure the methods are appropriate
- Advise on &/or co-produce a recruitment strategy
- Review questionnaires & data collection methods

- Increase the likelihood that results of research are implemented, by adding validity to the findings
- Develop patient information for new services / interventions within services

- Suggest ways to disseminate results
- Jointly present findings at conferences & forums
- Inform local patient groups / services
- Assist in getting findings published on charities / voluntary organisations websites
- Distribute results to their informal networks
- Co-produce summaries of findings
- Co-write publications

- Evaluate & recommend
- Implement / put into practice

- Continue to be involved with the study to maintain focus & address issues as they arise
- Collaborate with researchers to evaluate the research process
- Reflect on their role & what they have learned

- Review &/or write plain English summaries, that are used in funding & ethics applications
- Co-present study to ethics / funding panels

- Affirm importance of research question
- Clarify the research question
- Inform &/or co-design the study protocol
- Ensure the methods are appropriate
- Advise on &/or co-produce a recruitment strategy
- Review questionnaires & data collection methods

- Join the project steering group
- Co-produce patient information sheets & consent forms
- Produce & pilot patient-friendly research updates
- Conduct interviews & surveys as a co-researcher

At each research stage, PPI representatives can review & edit documents, to ensure they can be understood by lay people.

- Review findings for agreement and clarity in the interpretations of the data
- Work with researchers in developing themes from data

Adapted from the INVOLVE Research Cycle
http://www.invo.org.uk/posttyperesource/where-and-how-to-involve-in-the-research-cycle/
When you start planning for the involvement of patients and in your research, it will help to consider the following from the beginning as they will each take time to address:

- Informing
- Ethics
- Safeguarding

**Informing**

It is very important for patients and the public to feel empowered to contribute to your research. Helping your PPI representatives to really understand what your research is about is vital to this, and will enable them to better support your research.

- **Explaining:** Research should be explained using straightforward and appropriate language, as concisely and clearly as possible.
- **Illustration:** A simple illustration in addition to your explanation may help convey complex ideas.
- **Application:** It can be helpful in engaging patients and the public with your research by showing them how it applies to them or an aspect of healthcare they have experience with.

**Remember:** this is not the same as a participant information sheet, as the patients and members of the public are not research participants.

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**Ethics**

You do not need to obtain formal (written) consent to involve patients and public in your research. This is because they are not acting in the same way as research participants. They are acting as specialist advisers, providing valuable knowledge and expertise based on their experience. As the involvement of patients and the public in research is voluntary, it is important that PPI representatives give their agreement to being involved and are aware of the:

- **Nature** of their involvement (e.g. virtual communication, attending meetings, working co-productively)
- **Significance** of their contribution (e.g. how their input and feedback will have an impact)
- **Any risks** of involvement as applicable (e.g. sensitive issues being discussed)
- **Implications** of being involved (e.g. any travel required, frequency & length of meetings)

They should also be able to say if there are any areas of involvement they do not wish to take part in.

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**Resources from NIHR INVOLVE on how to produce documents in simple English:**


**Health Research Authority Website for information on ethics and involvement:**

Safeguarding

Safeguarding is “protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect” (Care Quality Commission)

If you plan to work with vulnerable people for the purposes of your research, you have a responsibility to know your organisation’s safeguarding policy so that you know what to do should a safeguarding issue arise.

Vulnerable groups include: children and young people; people experiencing mental ill-health; and people with a visual or hearing impairment, physical disability, and/or learning disability.

Check: your organisation’s safeguarding policy and for any training that may be provided on how to manage safeguarding issues should they arise.

Finding PPI support and recruiting PPI representatives

Established PPI groups
You could contact an established PPI group or panel, who can offer advice on PPI and connect you to their group members to support the PPI in your research. A list of East of England groups is in the appendices, with summaries of what each group does, how to access support and who to contact.

Recruiting PPI representatives
You could also recruit PPI representatives specifically for your project, for example as members of a service user advisory group (SUAG), members of a steering group, or in a co-researcher type role. For this, you could:

- advertise with a call for expressions of interest / applications for the role(s) on offer
- ask colleagues to connect you with PPI representatives they already know
- approach charities, community volunteer services or support groups relevant to the community / condition / service area you are researching

Selecting from expressions of interest / application forms:

- plan how you will select PPI representatives e.g. any key criteria for shortlisting, interviews, choosing who to invite to the role
- be clear about the selection process in your promotion material so people know what to expect

“Create engaging flyers; use twitter, set-up a page on Facebook or LinkedIn; use website posts and newsletters to spread the word!”
Researcher

“Flyers could go in waiting rooms of services; public notice boards; backs of toilet doors in services, clubs, colleges and universities (especially good for sensitive research areas)”
Researcher

National directory of charities: http://www.charitychoice.co.uk/charities

INVOLVE guidance on involving young people in research

Example of an advert and link to a role description for PPI representatives
http://www.clahrc-eoe.nihr.ac.uk/2017/02/members-public-sought-join-ppi-coordinating-group/
WORKING WITH YOUR PPI REPRESENTATIVES

From the start of your project:

- **Have a research team member dedicated to PPI and its coordination**: give your PPI representatives that person’s contact and role details. Wherever possible, the team’s ‘PPI lead’ and the PPI representatives should meet before the project starts.

- **Plan to include at least two PPI representatives** as this enables some mutual support and varied perspectives.

- **Create a list and descriptions of the roles / activities for the PPI representatives** to enable discussion, clarification and management of expectations for both the researchers and the PPI representatives. It also enables representatives to choose how involved they want to be according to their expertise, comfort and availability.

- **Set up mechanisms to record the PPI impact.** For example, keep a log of actions taken as a result of the PPI and the impact of these. Also, record those actions not taken and why.

- **Start planning ahead for ending involvement** as it will be valuable come the end of your project. (See Section 7)

**Link to INVOLVE role description template:**

**Training**

It’s important to consider any training needs of your PPI representatives as soon as possible, and to review these throughout their involvement. Ensure you have allocate enough time and resources to this as needed.

**Generic**

Representatives from PPI groups may have already received training in the research process, which could be basic (e.g. key research terms, how to review documents, and differences between qualitative and quantitative research) to very comprehensive (e.g. for co-researchers throughout the research cycle).

**Specific**

Even if they have had generic training, PPI representatives may need training specific to your project e.g. the type of research, research governance, methodology, analysis of qualitative or quantitative data, writing, and presentation skills.

**Check:** training being provided locally. Inform your representatives of any relevant training and support their attendance. See the link to NIHR organisations below, or check with local groups in appendix 2.

**NIHR Organisations that provide regional PPI in research training:**
NIHR Research Design Service (RDS) http://www.rds.nihr.ac.uk/
NIHR Clinical Research Network (CRN) https://sites.google.com/a/nihr.ac.uk/building-research-partnerships/courses/map
MEETINGS
The following points are good practice and will help your PPI representatives feel properly supported to attend and fully participate in any meetings.

Before
Give plenty of notice and send agenda / any papers a week before by email and / or post.
Provide a phone number: in case of last minute difficulties (e.g. of dedicated PPI person in research team and / or the venue)
Flexible timings: Consider evening or weekend meetings if you need to attract working age, parents and young adult participants
Convenient locations for the PPI representatives, for example that can be easily reached by public transport
Provide details and map of the venue: give your PPI representatives all details necessary to help them find the venue, especially for those coming for the first time
Check if the postcode works for Sat Nav / Google maps to avoid any confusion or delays
Ensure parking is as easy as possible, with disabled spaces. Remember to tell your representatives about parking, and book spaces for them when needed
Accessibility: make sure rooms are accessible, venues have disabled toilets when needed and that there is a hearing loop
Make sure you know everyone’s dietary requirements for refreshments and meals
Get expense claim forms ready: provide these in whichever format your PPI members can use them.

During
Have copies of any paperwork sent to the attendees; do not assume that they have been able to print them out at home.
Comfort Don’t make the meetings last too long and plan breaks
Terms of Reference (TOR): It is good practice for the group to agree its own TOR at the beginning of their involvement and to review these occasionally
Check and agree the format of the meetings with the PPI group members
Run induction sessions to clarify expectations, roles (using the role description) and time needed. Introduce basic concepts of research, the importance of confidentiality and ground rules
Remember to give out claim forms / details of how to claim: your PPI representatives may need support with completing these.

After
Write and send minutes / summary notes to the PPI group. Summarise what happened and let them know what will happen next (email and / or post as necessary)
Don’t forget to process expense claims to ensure PPI representatives are reimbursed promptly
Supporting your PPI representatives throughout their involvement

Be flexible and open minded: Allow some flexibility to accommodate people’s skills, strengths, interest, availability and potential changes in circumstances. Be open minded about what perspective PPI members can offer.

Regularly review PPI roles and the expectations from both sides

Consider whether you are acknowledging and responding to the needs of your PPI representatives in terms of their diversity and culture.

Remember to acknowledge their involvement and contribution, for their own development and the development of the research project.

Provide ongoing feedback on the study progress and the impact of your representative’s input. Enable the PPI representatives to respond to your feedback (see below for more on feedback).

Use your plain language and lay summaries, explaining any jargon or avoiding it where possible.

Allow for additional time for your PPI representatives to read information and paperwork.

Encourage and support your representatives to keep a log of their involvement and impact. This will enable them to provide feedback on their involvement and assist researchers in demonstrating the impact of PPI in their research.

“it’s really important to keep in touch with PPI members between meetings and provide feedback on their involvement and the progress of the study to keep them engaged” PPI representative

“Take their [PPI reps.] views on board and give them feedback as to how their input has shaped the research. Be honest if you don’t agree with their feedback and have a conversation as to why” PPI representative

Feedback is really important to PPI representatives

Many PPI representatives say they don’t hear back from researchers after they have provided comments. At the minimum, thank your PPI representatives for their comments and acknowledge receipt (be aware that some NHS email addresses are unreliable and PPI representatives don’t know if their comments have got through). Additionally, keep PPI representatives informed of any ethics submission, funding application they have contributed to and study progress. Lastly, try to feedback on the impact of their comments (for example: send final documents showing changes that have been made).

See the CLAHRC PPI Feedback Project
http://www.clahrc-eoe.nihr.ac.uk/2016/05/impact-patient-public-involvement-ppi-completing-feedback-cycle/
Working out your budget
There are many costs you need to budget for from the beginning, to ensure your PPI representatives are adequately supported and reimbursed throughout their involvement. INVOLVE recommend that research aim to allocate 5% of project budgets to PPI activities, though more may be needed depending on the nature of the research.

“When PPI was not costed from the beginning we had to draw on other funds to recruit PPI members, causing delays”
Researcher

“When you’re putting you research bid together, try to have already established who you’ll be working with – means you can properly cost in what your PPI members needs”
Researcher

Refreshments
Provide refreshments and meals at any meetings, events, and workshops that your PPI representatives are attending as part of your research

Paying for any drinks and meals for PPI representatives when away from home. e.g. if they are interviewing participants at an NHS Trust Clinic or University office all day and would be there at lunchtime.

Time
PPI representatives can be reimbursed for their involvement time, but this may depend on their level/type of involvement and any organisational policies your work is governed by.

CLAHRC EoE follow the terms of its host NHS Trust policy on ‘payments to service users and carers’ which applies to PPI. This policy includes reimbursement rates for:

- **Preparation:** such as reviewing study documentation and policies; writing a presentation; and planning an event, workshop or seminar *(it does not include reading standard meeting papers)*

- **Presenting:** for example at meetings, workshops and events - which includes when jointly presenting with the researcher(s)

- **Participation:** attending training necessary for their PPI role, taking an active part in working groups, focus groups, meetings, panels, workshops etc. either as an attendee or in a co-facilitator type role.

‘Budgeting for Involvement’ from INVOLVE, which includes an online cost-calculator: [http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/](http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/)
Expenses

**Travel:** any own-car mileage and / or the use of any public transport.

**Postage costs** for your PPI representatives to return any paperwork or items by post. Advise them to add postage to the expense claim for or supply postage stamps / stamped envelopes for them to use.

**Overnight accommodation may be required** if your PPI representatives have far to travel and / or is required to attend meetings and events held over consecutive days. Organise this for the representative and paid for it in advance out of your PPI budget.

Check your organisations’ policies on payments for refreshments and meals, time and expenses. Where researchers in the team work for different organisations, it may be helpful to choose one policy by which to base the terms and rates for reimbursement on.

PPI representatives receiving benefits

It is important that if your PPI representative is receiving any benefits, that these are not affected by being reimbursed for their involvement and any expenses.

**Advice for your PPI representatives**

INOLVE have established a Benefits Advice Service for PPI representatives who are involved in any NIHR funded research project (or an NIHR organisation).

You can inform your representatives of this service without needing to know if they are receiving benefits themselves.

They can contact this free and confidential service and will just need to have the name of the NIHR programme funding the research.

They will not need to disclose their benefit situation to the service.

**Contact details:**
email benefits@invo.org.uk
phone 02380 595628.

Check the website below before passing on this information to your PPI representatives. It is for PPI representatives, and not researchers, but it is good practice to know where your representatives can seek advice.

INVOLVE benefits advice for PPI representatives
http://www.invo.org.uk/benefits-advice-service-for-involvement-for-members-of-the-public/

“Don’t forget to tell your PPI reps. exactly what they can claim for [for their involvement], they should not be out-of-pocket supporting your research”

PPI representative

“Remember to consider how much meetings will cost, so you can plan this into the project management. Payments to out study’s PPI members were £100 honorarium for preparation time and attendance to meetings, plus travel expenses. This equated to approx. £800 per advisory group meeting, which were held every 6-8 months. This limited the number of advisory group meetings that could be held”

Researcher
When to think about closing involvement – plan ahead

From the start of the research, be clear with PPI representatives about the time scale of the project. The role descriptions written at the beginning will help with closing involvement.

Dissemination activities

Involving PPI representatives in the dissemination of research findings can improve the impact and distribution of findings, and increase public engagement. It also helps bring the project to natural close providing a sense of completion for PPI reps.

The plan for the dissemination of research findings built into the research proposal and PPI representative involvement should be budgeted for.

PPI representatives can help with disseminating the findings by:

- producing Plain English summaries of findings for patient groups/charities/voluntary organisations
- distributing the results through their local networks
- jointly presenting findings with researchers
- advising on different avenues for disseminating results

“In dissemination of research findings, lay members can present to groups – this can be powerful for getting the message from the research across” PPI representative

Feedback

It is important to feedback to your PPI representatives; and to get feedback from them at the end of the project (just as it is throughout the project).

Feeding back to PPI representatives: Feedback to representatives could be verbal presentations, written documents or online. Remember to feedback:

- research findings, outcomes, what is being done with the evidence, any publications or outputs, and any further research
- what the impact of PPI has been on the research project; let them know what has been helpful and why

Getting feedback from PPI representatives: It is also important to collect feedback. It could be a discussion, feedback meeting, survey, online polls, or written in a letter. Feedback should include the topics of PPI representatives’ experiences, what they felt worked and what didn’t, how things could have been better organised, concerns and complaints, compliments and thanks, general comments.
**Acknowledgement**

It is important to acknowledge the representatives contribution to the project. Remember to verbally say thank you! Certificates of involvement could be given if appropriate (see links below).

**Future opportunities**

PPI representatives may be keen to get involved with other projects when your research comes to an end. They will have developed a research skillset and this could be useful in other projects. If you have their permission, you can pass their details to other colleagues, make introductions or keep their details on file for future projects. Or point them in the direction of online databases advertising opportunities (see links below).

**Managing emotions**

Finally, ending the project will be emotionally difficult both for the researchers and the PPI representatives. A strong relationship between the researchers and reps may have developed. PPI representatives may be relying on the group for emotional support.

The ending of the project is something that can be discussed in the final meetings. Group members can choose to stay in touch with each other if they want to continue to stay in touch for support.

You may want to point representatives to other sources of support such as local charities/support groups, disease specific groups.

"Acknowledge their [PPI representatives] involvement and contribution – for their own development as well as their validation" PPI representative

"advisory group meetings sometimes felt like therapy sessions" Researcher

_Please note: If you are working with vulnerable groups, it may not be easy or appropriate to transfer PPI reps from one project to another. PPI can require a large amount of physical, emotional and financial support for the representatives involved; other projects may not have the resources for this. PPI representatives will have been selected for your research because of their relevant experience to your project. Other research projects may not need their unique experiences. Talk to your PPI reps about this and manage their expectations of involvement in other projects._


INVOLVE directory of networks, groups and organisations that support PPI in research - [http://www.invo.org.uk/communities/invodirect/](http://www.invo.org.uk/communities/invodirect/)

NIHR opportunities for involvement - [http://www.peopleinresearch.org/](http://www.peopleinresearch.org/)
It is important and can be motivating for researchers to consider the benefits that PPI representatives can experience from getting involved in the research process.

**Development of knowledge and skills:**

**Training and skill development**
- Opportunities for training in research processes and how to get involved
- Gaining new skills, such as how to evaluate different information or give an interview, which may be useful with work or at home
- Learning about research in your region

**Attending conferences and events**
- For learning and interest

**Publications: Acknowledgements and Joint Authorship**
- Any involvement in publications can be used by PPI representatives to demonstrate their contribution and skill development in research writing.

**Personal and social**

PPI representatives can experience many other benefits from taking part in research. These may include:

- **Social:** meeting like minded people; having new and interesting conversations; being part of a support network
- **Sharing expertise:** being able to use their experience; making a valuable contribution; and having their voice heard.
- **Well-being:** the effect of the various benefits of being involved could help support self-confidence and a sense of well-being.

“[Involvement] gave me the opportunity to draw on my personal experiences in a positive way....... I found that contributing in so many different ways has helped enormously with boosting my self esteem”

PPI representative

And it’s not just good for PPI representatives..... “Beyond the benefits that PPI can have to your research, actively involving and working with PPI representatives can help researchers with motivation, acting as a reminder of their research is important. It’s also a great opportunity for meeting new people and forming new meaningful working relationships” Researcher

CLAHRC EoE Involvement pages, co-written with a CLAHRC PPI Adviser: http://www.clahrc-eoe.nihr.ac.uk/involvement/
Acknowledgements

We’d like to take this opportunity to thank all the member of the Steering Group for their insights, support, and vital input to the development and delivery of the Masterclass programme. We’d also like to thank all the PPI Representatives and Researcher representatives who contributed to the programme, for all their hard work in preparing for the classes and for their willingness to talk about their experience to enable shared learning. As such, they have all made significant contributions to this handbook.

We’d also like to thank members of the Public Involvement in Research group (PIRg) at the Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire. They reviewed and provided feedback on the handbook, which was significantly helpful in finalising it for dissemination.

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<td>CPFT</td>
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<td>CLAHRC</td>
<td>Collaboration for Leadership in Applied Health Research &amp; Care</td>
<td>CLAHRCs are funded by the NIHR to bring together a collaboration of the local providers of NHS services and NHS commissioners, universities, other relevant local organisations and the relevant Academic Health Science Network. They conduct applied health research across the NHS, and translate research findings into improved outcomes for patients. There are 13 CLAHRCs in England.</td>
</tr>
<tr>
<td>EoE</td>
<td>East of England</td>
<td>Our CLAHRC region covers Cambridgeshire, Hertfordshire, Norfolk and Suffolk, and parts of Bedfordshire and North Essex. Our academic partners are the Universities of Cambridge, East Anglia and Hertfordshire.</td>
</tr>
<tr>
<td>INVOLVE</td>
<td></td>
<td>INVOLVE is part of, and funded by, the NIHR to support active public involvement in NHS, public health and social care research. It is a national advisory group that brings together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.</td>
</tr>
<tr>
<td>NIHR</td>
<td>National Institute of Health Research</td>
<td>The NIHR is funded through the Department of Health to improve the health and wealth of the nation through research. It is a large, multi-faceted and nationally distributed organisation. It drives research from bench to bedside for the benefit of patients and the economy.</td>
</tr>
<tr>
<td>NIHR CRN</td>
<td>Clinical Research Network</td>
<td>Funded by the NIHR, the CRN provides an infrastructure which allows high-quality clinical research to take place in the NHS, so that patients can benefit from new and better treatments. It supports research across 30 different health themes. There are 15 CRNs across England.</td>
</tr>
<tr>
<td>NIHR RDS</td>
<td>Research Design Service</td>
<td>The RDS to provides design and methodological support to health and social care researchers across England to develop grant applications to the NIHR and other national peer-reviewed funding programmes. RDS advisers in bases across England offer a unique breadth of experience and a proven track record in improving research applications. Advice is confidential and free of charge.</td>
</tr>
<tr>
<td>PPI</td>
<td>Patient &amp; Public Involvement</td>
<td>PPI is where patients and members of the public are actively involved in research projects and in research organisations. The term ‘patient’ refers to anyone who sees themselves as a patient, service user or carer, and this is currently or in the past.</td>
</tr>
<tr>
<td>PPI Representative</td>
<td>Throughout this handbook, we have used ‘PPI representative’ for consistency. Other terms you may see / use include: lay member, PPI member, advisory group member, PPI Advisor, Co-researcher, patient representative, and expert by experience. These different terms may reflect the level or the type of involvement, but may be culturally / socially defined. Whichever terms you use with your representatives, ensure that it is consistent to avoid any confusion.</td>
<td></td>
</tr>
<tr>
<td>SUAG</td>
<td>Service User Advisory Group</td>
<td>SUAGs offer advice and expertise to researchers. SUAGs can be set-up for specific projects or research themes, where service users and / or carers will be approached for help with various stages of the research process. Researchers typically meet with the SUAG to get feedback on e.g. the protocol, study documentation and recruitment methods, which help them to make the study relevant and feasible.</td>
</tr>
</tbody>
</table>
Cambridgeshire

Patient and Public Involvement panel  
**NIHR Cambridge BRC at Cambridge University Hospitals NHS Foundation Trust**

**DETAILS**  
The CUH PPI Panel is a thriving Panel of some 60+ public members who review research documents and proposals. The Panel members are also available for focus groups and other involvement activities. We are also pleased to assist and support researchers working with their own PPI patient groups, proving advice for researchers and inductions for new PPI members. You can contact the Coordinator directly or book at slot at one of our regular PPI surgeries (held in collaboration with the Research Design Service).

**ACCESSING PPI SUPPORT**  
Contact the PPI Coordinator to discuss your needs and how the Panel might be able to help with your PPI.

**CONTACT**  
Anna Ellis, Patient & Public Involvement Coordinator  
Email: anna.ellis@addenbrookes.nhs.uk  
Tel: 01223 254620  
Web: http://www.cuh.org.uk/for-researchers/setting-project/patient-and-public-involvement

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Service User and Carer Group (SUCG)  
**Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)**

**DETAILS**  
The CPFT SUCG provides training and opportunities for service users and carers to get involved in local health research at all stages of the research cycle.

**ACCESSING PPI SUPPORT**  
If you are conducting research in CPFT (e.g. recruiting service users from CPFT services) you can contact the User and Carer R&D Manager for support with your PPI in research needs. The manager will identify people in the group who would be suitable (in terms of experience and knowledge) to get involved in your study.

**CONTACT**  
Iliana Rokkou, User and Carer R&D Manager  
Email: Iliana.Rokkou@cpft.nhs.uk / R&D@cpft.nhs.uk  
Tel: 01223 746009  
Web: http://www.cpft.nhs.uk/professionals/early-considerations_2.htm
## Cambridgeshire and Bedfordshire

**INsPIRE (patteNt and Public Involvement in Research) Cambridgeshire & Bedfordshire**  
Cambridgeshire Community Services NHS Trust

### DETAILS
Members of INsPIRE presently meet with researchers to discuss research ideas, review project documents and sit on advisory and steering groups. Many of the members have been trained to provide PPI at all stages of research.

### ACCESSING PPI SUPPORT
Researchers need to write a brief description (1 or 2 sides of A4 max) of:
- what their study entails
- what is required from the INsPIRE members (e.g. commenting on grants, taking part in steering group meetings, taking on co-researcher roles etc.).
- the time commitments and remuneration arrangements (where applicable)
- contact details of a research team member

Send this information to the R&D Manager, who will disseminate it to the INsPIRE group. Any interested member will contact the study team directly.

### CONTACT
Paula Waddingham, R&D Manager  
Email: Paula.Waddingham@ccs.nhs.uk  
Tel: 01353 652293  
Web: www.cambscommunityservices.nhs.uk

## Hertfordshire

**Public Involvement in Research Group (PIRg)**  
Centre for Research in Primary & Community Care (CRIPACC), University of Hertfordshire

### DETAILS
The PIRg adopts a 'hub and spoke' approach to membership and involvement. The 'hub' is a permanent centralised group with a core membership of around 15 people. The 'spokes' utilise local users of services, and existing PPI groups and networks for specific projects, to increase diversity and participation when and where appropriate. Members of the hub group are involved in a variety of ways depending on their experience, interests and capacity. Support and training are given to members.

### ACCESSING PPI SUPPORT
Contact the PIRg co-ordinator to discuss possibilities. The coordinator will share the information with the group to arrange support.

### CONTACT
Julie Mace, PIRg Co-ordinator  
Email: j.mace@herts.ac.uk  
Web: http://www.herts.ac.uk/research/centres-and-groups/cripacc/public-involvement-in-research-group-pirg
### INSPIRE
**Norfolk and Suffolk NHS Foundation Trust (NSFT)**

**DETAILS**
INSPIRE NSFT engages service users, carers and the general public in all NSFT Research activities, and trains members to enable their active and informed involvement. Members get involved in all stages of research including design, development of new research ideas, being named on grant funding applications, assisting and feeding back on the practicalities of live studies, sharing research findings and creating their own research. There are specific panels for youth, adult, and later life mental health research.

**ACCESSING PPI SUPPORT**
Contact the INSPIRE Co-ordinator and provide a two-sided summary of your research that is written in plain English. Outline the support you are looking for, and the coordinator can organise this through the panel where possible.

**CONTACT**
Rhianna Broadway, Inspire Co-ordinator
Email: inspire@nsft.nhs.uk  Tel: 01603 421158
Web: http://www.nsft.nhs.uk/Get-involved/Pages/research.aspx

### PPIRes (Patient and Public Involvement in Research)
**NHS South Norfolk Clinical Commissioning Group**

**DETAILS**
PPIRes enables and encourages volunteer members of the public to collaborate with researchers in local Trusts and Universities in Norfolk and Suffolk. PPIRes has a panel of approximately 70 lay members and works closely with researchers to develop proposals from initial idea through to dissemination. All volunteers are offered the opportunity to attend training on the stages in research and how they could contribute. Volunteers are from a wide range of backgrounds and many have used health services extensively and have a disability or play a caring role.

**ACCESSING PPI SUPPORT**
Contact the PPIRes manager or complete an initial contact form on the website, outlining your research and support needs.

**CONTACT**
Jacqueline Romero, PPIRes Project Manager
Email: jacqueline.romero@nhs.net  Tel: 01603 257053
Web: http://nspccro.nihr.ac.uk/for-academics-and-nhs-staff/ppires/
Across the East of England

NIHR Research Design Service East of England (RDS EoE) Public Involvement Team

DETAILS
The RDS EoE public involvement team are not a PPI group, but have a role in supporting researchers with planning PPI in their research and putting them in contact with the group most relevant to them in the region. The RDS EoE offer a small public involvement fund to support pre-award public involvement activities (where alternative sources of funding are not available).

ACCESSING PPI SUPPORT
Contact the Regional Public Involvement Lead for further information about applying for pre-award funds to support your PPI activity. Contact the relevant local lead for advice and support on planning your PPI activity.

CONTACT
Regional Lead and Essex
Tracey Johns, Regional Public Involvement Lead
Email: tracey.johns@essex.ac.uk / rdsc@essex.ac.uk

Local leads
Cambridgeshire & Peterborough: Andrew Sharpe Andrew.sharpe2@nhs.net
Bedfordshire: Nasreen Ali Nasreen.Ali@beds.ac.uk
Hertfordshire: Janine Hawkins j.hawkins3@herts.ac.uk
Norfolk & Suffolk: Lisa Mcdaid L.Mcdaid@uea.ac.uk

Web: http://www.rds-eoe.nihr.ac.uk/public-involvement/ppi-for-researchers/

National

INVODirect

DETAILS
Set-up by INVOLVE, this online resource is a national directory of networks, groups and organisations that support PPI in NHS, public health and social care research. Individuals or networks, groups or organisations can access information and make contact with others who are carrying out similar work.

ACCESSING PPI SUPPORT
Researchers can use the resource to find details and contact information of groups in their region, who could support PPI planning and activity.

CONTACT
See http://www.invo.org.uk/communities/invodirect/ for contact details of each group.