

Collaboration for Leadership in
Applied Health Research and Care
Oxford

Welcome Pack for Patient & Public Involvement (PPI) Contributors



We are delighted that you have joined us



Welcome to your new role as a Patient & Public Involvement (PPI) Contributor.

We are delighted that you have volunteered in this way and everyone involved in our research appreciates your willingness to help, and the time and effort that you will put in. We hope that you will find the involvement interesting and rewarding.

We hope that this Welcome Pack will answer the questions that you have and help you and the project(s) you work on to get the most out of your contribution. If you are reading this online you can use control + click on any part of the contents table and it will take you straight to the section that you are interested in.

If you have any questions at any time please contact the PPI Coordinator;



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1 Who have you volunteered with?

This Welcome Pack relates to two separate organisations, both based in the same building in Oxford.

- 1) Nuffield Department of Primary Care Health Sciences, part of the Medical Sciences Division of Oxford University
- 2) Oxford CLAHRC (Collaboration for Leadership in Applied Health Research and Care). This organisation is funded by NIHR ([National Institute for Health Research](https://www.nihr.ac.uk/)) which is the Department of Health's means of funding medical and social care research.

You can find out more about both organisations from their websites and we encourage you to look at the research that we are involved with here;

- i. <https://www.phc.ox.ac.uk/about>
- ii. <https://www.clahrc-oxford.nihr.ac.uk/>

The CLAHRC's work is primarily undertaken by 4 Oxford University Departments in co-operation with many other partners – [Primary Care](#), [Psychiatry](#), [Population Health](#) and [NDORMS](#) (Orthopaedics, Rheumatology & Musculoskeletal).

These departments all work from different sites but the CLAHRC's core team is based in Primary Care at Radcliffe Primary Care Building on the site of the old Radcliffe Infirmary on the Woodstock Road in central Oxford. You may be asked to attend meetings at any of the sites where our researchers are based or occasionally in other settings in Oxfordshire.

2 Why do we involve Patients and the Public?

There are two fundamental reasons why we want your help.

1. Because it is a public right to know how public money is being spent (through taxes or charitable giving) and because it is the public who will be affected by the results of the research.

In our society this is a fundamental principle of how we organise our public sector organisations – so the public help to govern education, the police, local authorities etc.

2. Because it will improve the research.

The idea here is that the quality, relevance and impact of research will be improved by including the end recipients, like you.

We believe that both of these reasons are important.

We aim to have PPI in all of our research and in our governance structures.

3 What is Patient & Public Involvement in research?

PPI in research is about fostering active relationships between patients, the public and researchers.

Involvement in research means considering what research is to be done, how it will be done, how patients will be recruited and how the results may be used.

It is not taking part in clinical trials. If you take part in a clinical trial you are known as a participant in research.

All of the following groups of people will be described as PPI Contributors;

1. **Patient;** current or recent users of health services
2. **Public;** interested citizens who will have some level of engagement with the NHS, in the sense of being registered with a GP, but they do not have and have not recently had serious health problems.
3. **Carers;** family and friends of people living with an illness, disability or long-term condition which means they cannot manage without support. Carers will have their own experience of the health services provided to the person they support.
4. **Voluntary sector staff;** of charities and community groups that support people with health problems and can represent the broad range of issues that their clients raise with them. Examples of this would include the Alzheimer's Society, Diabetes UK, Parkinson's UK, Macmillan Cancer Support etc.

For this document the terminology chosen is PPI Contributor. However, this is one choice amongst several possibilities and there is no one term that is correct or even preferable. Other examples include lay member, patient advocate, citizen partner, research consultant, expert by experience, PPI representative etc.

As a member of the public, a specialised knowledge of the relevant research is not needed in order to be involved in it. Neither are you required to be a medical expert.



You may be asked to speak about your 'lived experience'. This might be of a condition or illness that you have or have had. It might also be of your experience of using health services.

You do not have to have had an illness to contribute in this way, as some of what we research will be about people's experiences of going to the GP, which everyone does!

What is important is that as a PPI Contributor you are able to bring your own knowledge and experience to the research process, whether as a patient or from your work or personal life.

4 How will we support you?

The PPI Coordinator will send you a range of opportunities and it is entirely up to you which you choose to respond to.

If a research project appoints you to work with them (they will vary in how they choose who they want, but this will be made clear in the advert) you will then be contacted by a specific researcher.

This researcher will provide you with enough information to enable you to contribute:

- ✓ Basic details about the project and what researchers hope to achieve
- ✓ Their name and contact details and hours if they are part time
- ✓ How you will be asked to contribute? This should include how your input will be used e.g. to re/define the research questions, to help write the lay summary etc.
- ✓ How often you will be asked to attend meetings, how long meetings will last and if they will take place in central Oxford. The overall time commitment expected of you
- ✓ How long the project will last.
- ✓ How any specific support needs you have will be met (for example if you wear hearing aids)
- ✓ Whether you will be reimbursed your expenses and how to claim.

- ✓ Whether you will be paid an honorarium and if so how much and what information you need to provide.

Other support from the project will vary depending on the nature of your involvement but will include things such as;

- ✓ being sent papers in good time before a meeting
- ✓ phone contact to answer your queries
- ✓ additional information to help you to contribute
- ✓ regular feedback on the progress of the project

At Appendix 3 of this document you will find some health glossaries which may help explain some of the jargon that you will inevitably encounter. However you should always feel free to ask researchers to explain anything you do not understand. We will try to avoid acronyms and jargon and you should feel free to challenge us on this.

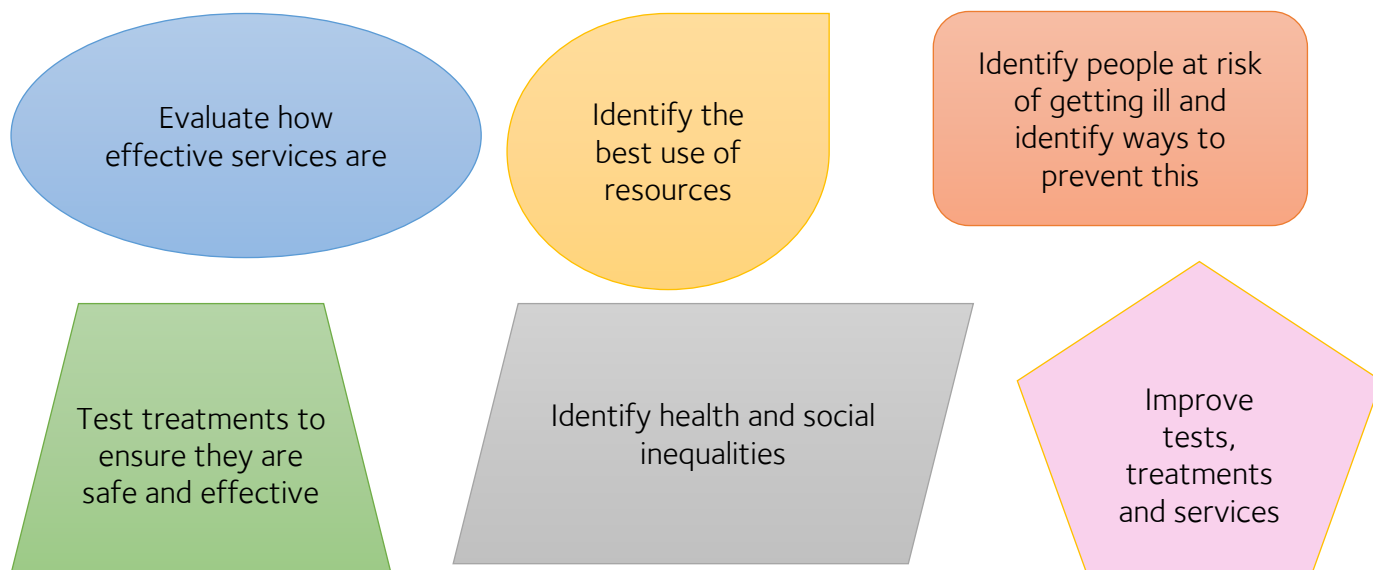
5 How is our research organised?

Some staff spend their whole time doing research, whereas others carry out research alongside other roles, such as being a GP, nurse, consultant or other health care professional.

Much of the research in Oxford is done jointly with other universities from around the country and also overseas.

| | |
|----------------|---|
| Primary care | is health care provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment. In the NHS this is mainly your general practice i.e. your GP. |
| Secondary care | is hospital treatment, named because it often requires a referral from your GP. |

Our research aims to;

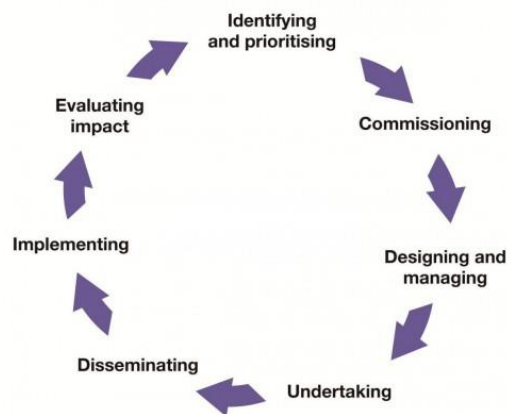


6 How does patient & public involvement work in practice?

Not always, but often, you will be asked to contribute by attending meetings. The main types of meetings that you may get involved with are;

| Name | Definition |
|--------------------------|--|
| Trial steering committee | Group that has overall strategic and management responsibilities for the research throughout its funding period. Will include clinicians, researchers, statisticians, health economists etc. and at least 2 PPI Contributors |
| Advisory group | A group of PPI Contributors called together to focus specifically on certain questions. This will be facilitated by 1 or more researchers. |
| Stakeholder group | An advisory group that contains PPI Contributors but also clinicians, researchers and others relevant to the study. |

Patient and Public involvement can take many different forms as each topic of research varies. However, PPI in the research cycle could include some of the following ways for you to be involved in meetings as listed above:



You could be involved in helping **to identify and prioritise** research so that you influence what will be researched. You will be able to ensure that the research priorities set are the same as those of the people who have the condition being researched or use relevant services.

You could be involved in helping to **commission** research. Commissioning is deciding what research will be funded and making the arrangements to ensure that best value for money approaches are agreed with the funder. (This is less likely in our organisations currently).

You could be involved in the **design** of research helping to ensure that the research is relevant to people’s needs and also that the research question and outcomes are clear.

You might get involved in **undertaking** the research such as:

- undertaking library-based research
- carrying out interviews
- running focus groups
- developing research tools and information
- gathering and reviewing documentary evidence
- analysing and interpreting the results of research

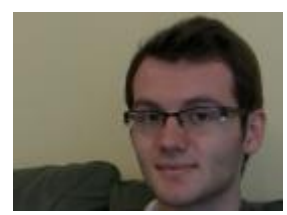
You could be very helpful to the researchers in using your personal and professional contacts to ensure that the findings are widely **shared and disseminated**. This might include if you were interested, speaking at professional conferences with the researcher.

Your involvement in research can provide a route to **implementing** change and improvement in the issues that most concern people and so can lead to new improved services and changes in practice.

You could be involved in **monitoring and evaluating** the project.

7 How can you find out more about what PPI is really like?

You can learn a lot more about what motivates PPI Contributors but also how they have contributed by going to the [Healthtalk](#) website.



This website compiles video interviews and has sections on:

The [PPI Contributor perspective](#)

The [researcher perspective](#)

8 How might your involvement help?

Your involvement can provide a route to implementing change and improvement in areas that concern people most and lead to new improved services and changes in practice. For example, you may help:

- identify what research is important to fund. This may be different from the research that researchers think should be done
- increase the chances that funding applications will be granted by being involved at that early stage
- influence the way research is planned, for example by working on the research proposal, and how it will be carried out
- improve the experience for people taking part in the research by influencing the way the research is carried out
- influence the outcome measures of a research study, by suggesting measures that are important to people who use services
- increase the number of participants who agree to be in the research by making sure they are given good quality information and are treated with respect
- make it more likely that the findings of research are provided in user-friendly ways and publicised widely so that the wider public get to hear about it

9 What do we need from you?

We are grateful for all of your input. The following are some of the attributes we hope you can contribute:

- the ability to express your views confidently at meetings attended by a range of professionals and/or other PPI Contributors
- the ability to keep asking questions until you get enough information or an explanation to understand fully what people are talking about

- a willingness to listen to, and consider, different views
- an ability to challenge current thinking in ways that are both creative and supportive
- the ability to manage and plan your own time
- the commitment to attend meetings as agreed
- the commitment to prepare for meetings by reading information, which will normally be sent to you 1 – 2 weeks in advance
- to give and maintain a firm commitment to keep our research confidential and to maintain confidentiality about all aspects of meetings attended



The amount of time that you will be asked to give will vary widely between projects but it is important that you only get involved with a project if you can provide the time that they need.

10 What will you gain?

- An opportunity to influence world class research
- An insight into how health care research is carried out
- New skills for your C.V.
- Learning about why research matters
- The satisfaction of making a contribution and helping to improve services
- More information about your own condition or that of someone you care for

11 What will we give you?

Expenses

Each project will reimburse your out of pocket expenses.

We pay expenses against receipts and encourage you to make claims as soon as possible after the event. You will be provided with information on how to claim for any appropriate expenses incurred.

We strongly recommend that you keep a record of all expenses and when you claim for them and receive payment so that you do not lose track of whether you have received payment.

Reimbursement

Some projects offer remuneration. You are completely free to accept or decline the offer. Please read the [Patient & Public Involvement Payment Policy](#) to understand your duties in terms of informing HMRC of any income from this.

For those on State Benefits there are two confidential free services providing advice and support and it is **strongly recommended** that if you are in receipt of State Benefits you contact the appropriate helpline to ensure that there are no adverse effects of your involvement work, prior to beginning. You will need to find out from your main research contact who is funding the research before you contact the helpline.

If the research study you are involved in is **funded by the NIHR** the process is:

- contact INVOLVE on benefits@invo.org.uk or 023 8059 5628, 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.

If your research study is **funded by NHS England** the process is:

- Contact Bedford Citizens Advice Bureau via email involve@bedfordcab.org.uk with a brief summary of the query, or by calling 01234 330604.

N.B neither service is 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).

If you have any questions about this speak to your main contact or the PPI Coordinator. We do not want payment to become a burden or worry. It is routine practice and should not cause you any difficulties.

Training

You will be notified of any training opportunities available and you are encouraged to take them up if you feel you would benefit.

Review

Occasionally you should be given the opportunity to review how your involvement is going with your main contact. At the very least you should have this opportunity annually. You should also expect to be given feedback on:

1. the outcomes of the research work
2. the outcomes of the PPI input into the research work

In both cases you should feel free to respond to this feedback.

Leaving a project

Since you are a volunteer you may leave the project at any time. As we value your input however, we would ask you to give us as much notice as possible if you intend to leave.

If you wish to leave a project but would be happy to work on another one then we would very much welcome that and you should contact the PPI Coordinator to discuss other options.

It is also possible to find other opportunities in the Thames Valley beyond Primary Care at [Patients Active in Research](#) or nationally at [People in Research](#).

Project Completion

At the end of your project we aim to give you the opportunity to do some other involvement work if you choose, and if a suitable project is available. If this is not offered to you please contact the PPI Coordinator who is keen to ensure that your skills, knowledge and enthusiasm are not lost to research.

Please contact your main contact on the research project you are linked to or the PPI Coordinator if you have any queries about your involvement.

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Appendix One: 'Top tips' for new public Contributors

(The following top tips have been copied from Kath Maguire, a former public Contributor at National Institute for Health Research Central Commissioning Facility:

http://www.nihr.ac.uk/CCF/PPI/Top_tips_for_new_public_members.pdf)

Before a meeting

- * Spend some time reading and digesting what the research is about in the plain English summary
- * On thinking about the project consider
 - o Potential patient benefit
 - o Summary of PPI involvement and strengths (how active is it and at what stages?)

- What is being asked of patients, and is it practical?
- Financial considerations of PPI (are there the funds necessary available?)
- Key concerns
- Potential opportunities for improving PPI
- Any other issues

Make sure you have prepared a very short and to the point summary of your views, keeping the points you make clear and concise – so that your most important points can be summed up in a few sentences. Don't expect to be able to make all your points during a meeting so prioritise the most important before you attend.

At the meeting

- * If you have a more general issue, think about what may be the best time to raise it. At the start of the meeting? AOB [any other business] at the end? Is it worthwhile talking to the Chair first and letting them know you have something you want to bring up, asking them what would be the best time to do it?
- * Feel confident - you've been appointed because you have shown that you can and do speak appropriately to Patient & Public Involvement and protection issues. There's no need to over prepare, but be prepared!
- * Don't worry about being 'right'. It can be easy to play yourself down and think that the other professionals on the committee are all experts, therefore they know more than you. However, you're an expert at what it's like to be a patient, and the experiences & opinions that you bring are valid and worth sharing.
- * Remember that everyone is on the same side; there is no 'them and us'; if people don't accept your points it's not because you're a PPI member. It's because they disagree.
- * Try not to reflect only your own health experiences, but use those experiences to present more general points, that you believe have affected others too.
- * If sometimes you don't feel confident about speaking out, or asking what something means, remember that the non-PPI people round the table are specialists in their own field, and don't necessarily feel confident themselves on speaking about all proposals or all aspects of a particular proposal.
- * What's presented as a medical problem may not be; try some lateral thinking to analyse it in a different way.
- * Think about how you say things so that they do not come across as a criticism of the group or the individuals within it. Start with any positives.

- * Remember communication is a two-way street which often involves both talkers and listeners with different levels of competence in these tasks. Sometimes you might have to listen harder, ask more questions or explain your own points differently.
- * Be succinct – sometimes more is less, particularly when there is a lot to get through and a lot of voices to be heard.
- * You're doing this because you want to; enjoy it, and stop doing it when it stops providing "job satisfaction".

Designing the research

A Research Question is a statement that identifies the phenomenon to be studied. A strong research idea should pass the “so what?” test. What is the benefit of answering this research question? Who will it help (and how)?

A research focus should be narrow, not broad-based. For example, “What can be done to prevent substance abuse?” is too large a question to answer. It would be better to begin with a more focused question such as “What is the relationship between specific early childhood experiences and subsequent substance-abusing?”

To develop a strong research question some of these questions need to be answered:

- » What are the important research questions in this field? Has the [James Lind Alliance](#) worked on setting priorities in this field? (a non-profit making organisation which brings together patients, carers and clinicians to identify and priorities the top 10 uncertainties – or unanswered questions – about the effects of treatments which they agree are most important)
- » Has a great deal of research already been conducted in this topic area?
- » Has this study been done before? If so, is there room for improvement?
- » Is the timing right for this question to be answered? Is it a hot topic, or is it becoming obsolete?
- » Most importantly, will my study have a significant impact on the field?

Funding of research

There are various local and national organisations that fund health and social care research, for example:

- National Institute for Health Research (NIHR),
- Voluntary organisations (e.g. Wellcome Trust, Joseph Rowntree Foundation, Macmillan Cancer Support, Alzheimer’s Society)
- Research Councils (e.g. Medical Research Council)
- Industry (e.g. pharmaceutical companies)

Most funding in primary care research is spent on the salaries of researchers. In some studies there may also be expensive equipment to purchase.

Research usually starts with decisions being made about what research needs to be funded. In some research programmes the topics for research are decided in advance by research commissioners. In other research programmes it is up to researchers to put forward proposals for specific research projects that they wish to undertake. This is called responsive funding.

Members of the public are increasingly getting involved in advising research commissioners and researchers about what broad areas of research should be funded.

Obtaining funding for research can be complicated. Often researchers have to compete for the money to carry out their research plans. To apply for funding, researchers usually complete a research proposal or research grant application form. The application form asks for specific information including a description of the research and why it needs to be done, information about who will be doing it, and a detailed estimate of how much the research will cost. Our PPI Contributors often help researchers with a grant funding application, so nobody can be sure that this will be successful and the research will go ahead.

Research commissioners are increasingly asking researchers to include information about their plans for public involvement in the research.

Sometimes, members of the public work with researchers or take the lead in applying for funding for research that they are interested in.

Carrying out research

Once funding has been agreed the research may also need permission from an ethics committee and research governance before it can get under way.

Carrying out the research includes collecting information, for example by sending out questionnaires or interviewing people, analysis and interpretation of the information collected followed by writing up the findings of the research.

There are two main approaches to research
– Quantitative and qualitative research.

The choice of a quantitative or qualitative approach depends on the type of information that is needed to answer a question. It is not unusual for both approaches to be used as part of one research project. Both research approaches draw on a large number of different research designs and research methods.

Quantitative research tends to be large scale in its approach to the research topic as it aims to be Contributor of the group being researched. It focuses on numbers and asks questions such as – ‘how often?’, ‘how many?’ or ‘how much?’

These questions help for example to:

- collect measurements of people’s pain on a scale from 1 to 10
- record information about people’s diet and lifestyle habits.

Randomised controlled trials or systematic reviews are examples of research designs used in quantitative research. The information is collected through various research methods such as survey questionnaires, tests and observations. Statistical analysis is then used to make sense of the information collected in this way.

Qualitative research focuses on people's attitudes, views and how they make sense of their experiences and the world in which they live. It asks questions such as 'what does it mean?', 'in what ways?' or 'what does it feel like?'

Compared with quantitative research it explores aspects of a research topic in greater depth and usually with a smaller number of people.

It often involves asking people for detailed descriptions and explanations. For example:

- how would you describe your pain?
- what are your views on eating fruit and vegetables every day?

Qualitative research approaches sometimes draw on action research, emancipatory or participatory research designs.

Qualitative research methods include in-depth interviews, focus groups, diaries and videos, as well as observations. The information is analysed and reported in a non-numerical way.

Systematic Reviews

It is also very common for the research to begin with a systematic review. Systematic reviews are reviews of the published (and sometimes unpublished – which is called grey literature) research on the topic of interest. It collects and critically analyses multiple research studies or papers, using methods that are selected before one or more research questions are formulated, and then finds and analyses studies that relate to and answer those questions in a structured methodology. The intention is to provide a complete, exhaustive summary of current literature relevant to a research question. Systematic reviews of randomized controlled trials are key in the practice of evidence-based medicine. Sometimes the research study is entirely a systematic review.

Dissemination – communicating the research findings

Dissemination involves communicating the findings of the research to a wide range of people who might find it useful. This can be done through writing reports and articles, giving talks, producing a DVD or audio tape on the research.

It is also very important to feed back the findings of the research to the research participants who took part in the study.

Development – putting the research into practice

If the findings of the research are to be implemented this is usually done by health care practitioners or managers.

However not all research is used or results in changes or developments to policy, services or treatments. Some of the reasons for this are:

- other information also needs to be taken into account when making decisions
- limits on funding prevent some research findings being put into practice
- sometimes the findings are controversial and agreement cannot be reached as to how to take them forward
- sometimes the research does not provide the answers and more research is needed

At the end of the research project, researchers may involve members of the public in monitoring or evaluating the research to see what it has achieved, as well as to help identify what questions remain unanswered, or to identify new questions and topics that have arisen.

Appendix Three: Health research glossaries for PPI Contributors

| | |
|-------------------|---|
| NHS Confederation | http://www.nhsconfed.org/acronym-buster |
| INVOLVE | http://www.invo.org.uk/resource-centre/useful-information/jargon-buster/ |
| NIHR | https://www.nihr.ac.uk/patients-and-public/why-join-in/definition-of-terms.htm |
| GET-IT Glossary | http://getitglossary.org/ |

Appendix Four: PPI newsletters

Find archived editions of PPI Pulse, the newsletter written with just you in mind – <https://www.clahrc-oxford.nihr.ac.uk/public-involvement/public-involvement-newsletters> You will now start to receive this newsletter straight to your inbox once a quarter.

You will also find here the most recent edition of Involvement Matters, the ebulletin that you will now start to receive monthly. It includes involvement in health matters beyond research, so for example health service provision, education and commissioning.



Acknowledgements

This document was produced by the PPI Coordinator with contributions from Tricia Carver, Derek Day, Margaret Glogowska, Bernard Gudgin, Peter Kirby, Nathan Hill, Carol Munt, Derek Shaw, Bob Vause, Martin Wood and David Yeomans who helped us with developing this welcome pack providing a public and researcher perspective and helping us to ensure we cover the kinds of information that PPI Contributors need, when first getting involved in research.

Thanks again to Anna Hughes and Anne Knowland who helped by reviewing it from a PPI Contributor perspective for a substantial re-write in November 2016.

We welcome your views on how helpful or not you find this pack – please let us know if anything is unclear and how we could improve it.